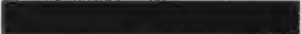


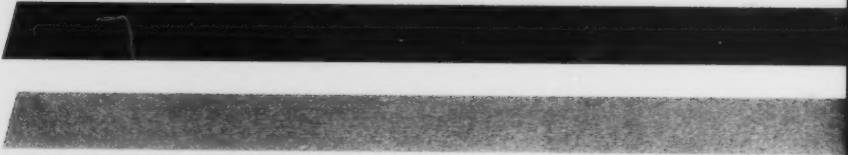


Health Services
and Promotion Branch
Working Paper


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KNOWLEDGE DEVELOPMENT FOR HEALTH PROMOTION:

A CALL FOR ACTION



Canada 

Knowledge Development for Health Promotion: A Call for Action*

Health Services and Promotion Branch
Health and Welfare Canada

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* The views expressed in the summaries of the research papers do not necessarily reflect the views of Health and Welfare Canada.

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PART I

THE KNOWLEDGE DEVELOPMENT PROCESS

1. PURPOSE OF THIS REPORT

The purpose of this report is to encourage and invite broad participation in the health promotion knowledge development process. Health promotion is both a national and a local endeavour, and the invitation is open not only to professionals from a variety of disciplines, but also to academics, community volunteers and activists, policy-makers and planners from many sectors and every jurisdiction, and to all Canadians who are concerned about health.

The report is also intended to serve as a vehicle for disseminating the results of research commissioned by Health and Welfare Canada on the elements of the Health Promotion Framework, presented in its landmark document, *Achieving Health for All*. It is hoped that the publication of these papers will help to stimulate further discussion and research, and provide readers with a basis for putting health promotion into practice in their own spheres.

Like the Health Promotion Framework itself, this report will stimulate many questions. If it does this, and motivates interest in answering those questions, it will have served its purpose.

2. ORGANIZATION OF REPORT

This report consists of two parts:

Part I: *The Knowledge Development Process* provides the background to the report, summarizes the key features of the Health Promotion Framework, examines the elements of knowledge development, and reviews Health and Welfare Canada's key dissemination and research activities to date. Finally, it considers what future steps may be taken to advance the process of knowledge development.

Part II: *Research Reports* provides highlights and summaries of twenty-four literature reviews and research reports commissioned by the Working Group on Research Priorities in Health Promotion and Disease Prevention, established by Health and Welfare Canada. The main basis for organizing these reports is the Health Promotion Framework, contained in the public discussion document entitled *Achieving Health for All*. The reports are presented in three sections: The Challenges, The Mechanisms and The Implementation Strategies. Two papers cut across the various cells of the framework, dealing largely with

methodological issues. They have been placed under the Strategies heading.

3. BACKGROUND

The nature of health promotion

Health promotion is difficult to define. It is something quite original, which is not health care, or health education, or health administration, or public health, although these all form part of its lineage. Health promotion is more than the sum of its parts; it encompasses in a new synthesis elements of all the above health fields, as well as fields which in the past would have been regarded as falling outside of the health domain.

The nature of health promotion, its existence as a separate field, and its efficacy, are all the subject of considerable discussion and debate. This is indicative that although still very much in its infancy, health promotion is alive and well and gives every sign of reaching a healthy maturity.

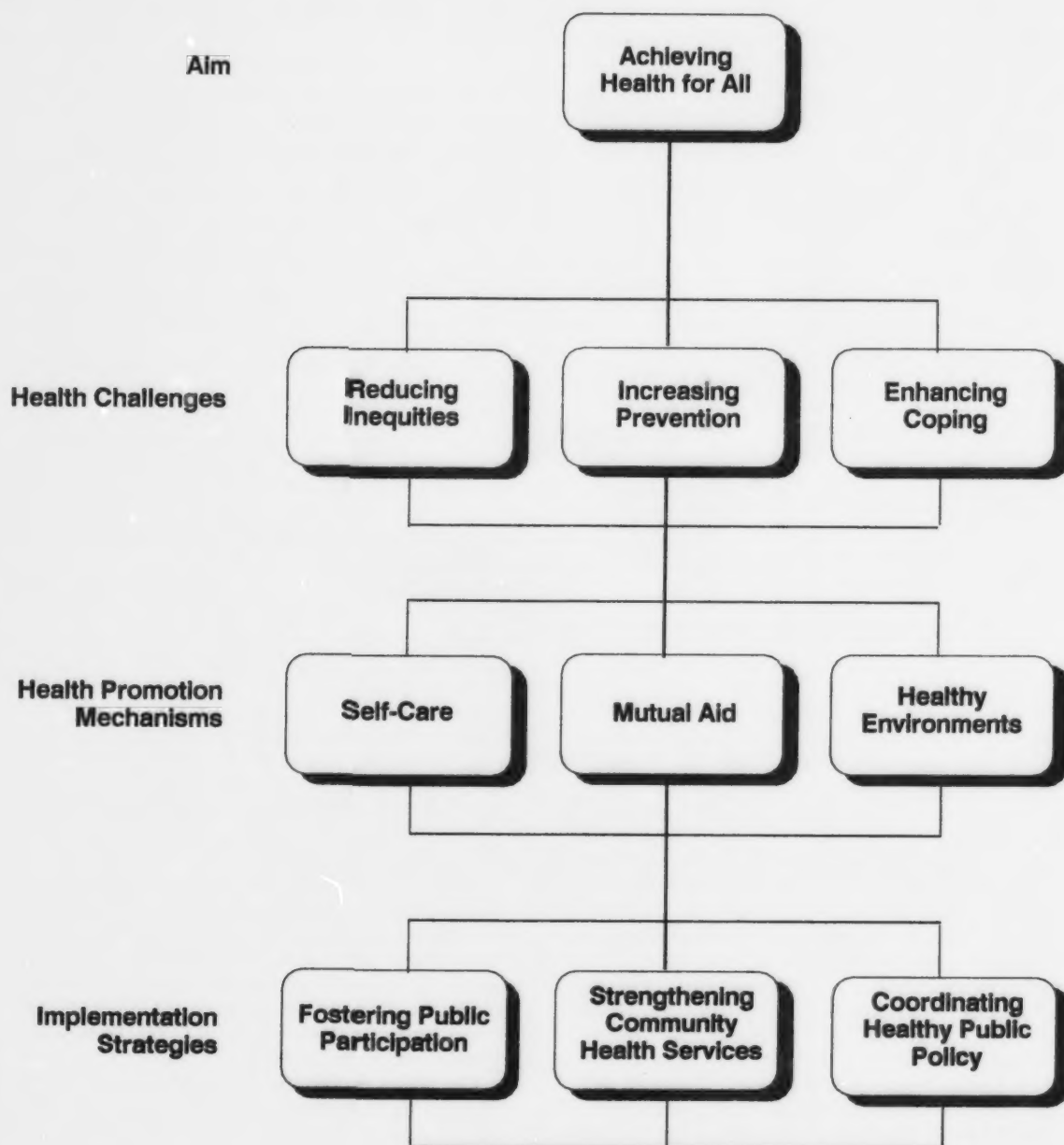
Achieving Health for All and the need for more knowledge

Achieving Health for All: A Framework for Health Promotion was released by the Minister of National Health and Welfare, the Honourable Jake Epp, in November, 1986. Building on the concept of health as a dimension of the quality of life, the paper identified certain national health challenges which Canadians needed to meet in order to significantly improve health and quality of life in this country. The challenges identified—those of reducing inequities, increasing prevention and enhancing people's capacity to cope—continue to drive Canadian initiatives in the health promotion field.

To meet these challenges, the document proposed a "health promotion approach." Drawing its ideas from several arenas—public health, health education and public policy, for example—the new approach focused less than earlier approaches on individual lifestyles and more on the ability of the environment to influence people's health, in both positive and negative ways.

The health promotion approach involves the use of three "mechanisms" (self-care, mutual aid and the creation of healthy environments) and the adoption of three "implementation strategies" (fostering public participation, strengthening community health and coordinating healthy public policy).

A Framework for Health Promotion



The conceptual links among these elements—the challenges, and the mechanisms and strategies aimed at overcoming them—were illustrated in *Achieving Health for All*, which summarized the relationships as follows:

... health promotion implies a commitment to dealing with the challenges of reducing inequities, extending the scope of prevention, and helping people to cope with their circumstances. It means fostering public participation, strengthening community health services and coordinating healthy public policy. Moreover, it means creating environments conducive to health in which people are better able to take care of themselves and to offer each other support in solving and managing collective health problems.

The document concluded that it would take time to give meaning to health promotion, and that a vital element in the process would be nationwide discussion, enabling Canadians to assess the implications of the framework's concepts. At the same time, the document pointed out that individuals and groups across the country were already engaged in activity consistent with the new health promotion approach. "The body of knowledge and experience is accumulating rapidly," it stated.

In providing a basis for consultation on the framework concepts, *Achieving Health for All* also clearly established knowledge development as a fundamental, if unexpressed, fourth strategy of the Health Promotion Framework.

Towards a broader perspective

In proposing a new paradigm for health in Canada—one marked by a socio-ecological, multi-disciplinary orientation—the framework opens the way for fresh linkages to be made, and for the forging of new and refreshingly different kinds of relationships among the ever-widening circle of players in health. By shifting the focus from an individual to a broader environmental perspective, the framework invites the involvement of disciplines, sectors and interests which have not previously been accustomed to regarding health as part of their domain.

In the new thinking, health becomes the concern and the responsibility of the collective as well as the individual, and an important issue for all sectors. By emphasizing the necessity for collaboration and coordination across political, geographical and professional boundaries, the framework brings conscious recognition of important but often ignored interdependencies. It is, in effect, an invitation to partnership, a call for action.

- Health professionals are called upon to recognize the role of lay persons and to

work with them in defining community health problems and solutions.

- Professionals in various other fields engineering, architecture and urban planning, for example must recognize the intimate links between their activities and a community's health, and work in consultation with the health field.
- Government departments are called upon to communicate with one another on health issues, and to create structures which facilitate this process. They are also required to increase the involvement of consumers and client groups in the process of policy development.
- Academics of various disciplines and convictions are called upon to build bridges, both within their own community and outwards, towards the private, public and voluntary sectors.
- Virtually all sectors, suppliers, consumers and interest groups are challenged to examine the effects of their decisions on the health of Canadians.

This report reflects the emergent state of health promotion, both the concept and the process. It represents an initial attempt to pull together and to connect up some of what is known so far, to consider what else we need to know, and to explore how to find this out. Its intent is to stimulate all relevant parties, particularly those from beyond the traditional health sphere and those outside the governmental structure, to become involved in health promotion, to ask questions and to find new ways of interpreting and using the answers and sharing overall knowledge. This report represents the first step in what promises to be a long and difficult, but exciting process.

4. KNOWLEDGE DEVELOPMENT: ELEMENTS AND ACTIVITIES TO DATE

The elements

The federal government considers that the further development of knowledge concerning the framework's ideas must be an important priority if we are to give shape and focus to health promotion, and facilitate the use of the framework. Any valid definition of the term "knowledge development" must encompass two distinct concepts:

- sharing existing knowledge (knowledge dissemination)

- adding to the knowledge base (research, or collecting information for action)

This expanded interpretation of knowledge development as it applies to health promotion suggests the need for a correspondingly "broad-sweep" approach to the task of designing a knowledge development strategy. Clearly, parallel activities of two different kinds are required, each with several sub-components.

Disseminating activities, on the one hand, would include such things as publishing reports and other materials, sponsoring discussion sessions (workshops, seminars, conferences), building networks, modifying curricula (particularly with respect to professional training) and organizing ad hoc training sessions and courses—in short, all those activities which would serve to "spread the word" on health promotion and its key concepts and principles, and lead to a clearer understanding of the framework and its ideas.

Research activities, on the other hand, would encompass all steps taken for the purpose of increasing the current base of knowledge concerning health promotion. This would certainly include, but not be confined to, narrowly-focused research projects. It would also extend to literature reviews, community action studies and a host of other data-gathering and analytical activities (e.g., formal and informal surveys) and the use of qualitative as well as quantitative approaches, and of innovative methodologies.

Activities to date

The federal government took the view from the outset that the more broadly drawn, flexible and dynamic the knowledge development strategy could be, the greater would be the chance of achieving a genuine expansion of knowledge in the relatively unexplored field of health promotion. Health and Welfare Canada was anxious to ensure that disciplinary boundaries or research specialization should not be allowed to operate as a barrier to the accumulation and dissemination of knowledge, impeding the achievement of results over the long term. This position is reflected in the diversity of activities undertaken to date by the department as part of its health promotion knowledge development strategy.

To ensure that the framework's ideas are known, discussed and understood as widely as possible in Canada, and to promote research activities related to its key concepts, Health and Welfare Canada has taken action on both elements of the knowledge development process.

Dissemination: More than 360 000 copies of *Achieving Health for All* have been distributed through reprints in professional journals and

special mailings to major non-governmental organizations and academic institutions. In 11 of the 12 provinces and territories, federal-provincial exchanges have been held involving hundreds of representatives of provincial/territorial jurisdictions, as well as a multiplicity of voluntary and professional groups and organizations. Moreover, the Minister and his senior officials have incorporated content on the framework in over 60 speeches to professional and voluntary sector groups and organizations, and an interview with the Minister on the framework has been published in *Health Promotion* magazine (20 000 subscribers).

In addition, the framework has been presented and discussed at the meetings of nine federal-provincial advisory committees and working groups, including both the Advisory Committee on Mental Health and the Advisory Committee on Community Health.

There has also been a deliberate community-level strategy of dissemination. Thousands of copies of *Achieving Health for All* have been distributed to groups with strong community links, such as the Victorian Order of Nurses and the Canadian Sickle Cell Society, who are incorporating its concepts into their planning processes. With Health and Welfare Canada funding, the Canadian Public Health Association (CPHA) has sponsored workshops across the country on the framework strategy of strengthening community health. The criteria for project funding by the Health Promotion Contribution Program also reflect and publicize the framework's philosophy.

Within Health and Welfare Canada itself, a series of seminars has been held on health promotion, to raise awareness of the framework throughout the department. To sensitize the federal government at large to Health and Welfare Canada's activities and the framework's main ideas, the department has organized special presentations to Statistics Canada, Environment Canada and Secretary of State. At the international level, the development of the framework was used as the basis for a case study at the 2nd International Conference on Health Promotion, held in Adelaide in April, 1988.

The academic community has been an important target, as well as a principal agent, of this dissemination strategy. Consultations have been held with the University of Manitoba and York University on using the framework as the base for developing their first curricula on health promotion. Moreover, *Achieving Health for All* is now being used in the curriculum of Quebec's CLSC training programs, as well as in some universities. In the summer of 1987, the framework was used to struc-

ture the first national summer school on health promotion at the University of Alberta.

More than 30 members of Canada's research and health education community have also participated actively in the work of developing a health promotion research agenda, not only for the federal government but for the wider research community.

Research: Various activities have taken place within Health and Welfare Canada's Health Services and Promotion Branch, aimed at expanding the existing knowledge base on health promotion in general, as well as on the various framework's elements or "cells" (challenges, mechanisms and strategies).

A special committee assigned individual staff members to review:

- past and on-going in-house research related to the framework's cells;
- WHO and other reports which have made recommendations about health promotion/disease prevention research; and
- Directorate policy and planning documents, from the point of view of knowledge requirements.

In addition, staff from the Health Promotion Directorate's Health Promotion Studies Unit gathered views on research needs from program managers within the Directorate, and from representatives of the Health Services Directorate. As a result, three reports were produced, identifying research needs from both an international and a departmental perspective, and categorizing these needs according to framework cells.

As a complement to its own in-house review activities, the Branch has been consulting with outside groups of researchers, practitioners and others involved in the health promotion field. For example, a working group co-sponsored by the

Health Promotion Directorate and the Extramural Research Programs Directorate and composed of experts from outside of the federal government was invited to consider how to develop a research strategy to aid in implementing the Health Promotion Framework and to define priorities for health promotion research in Canada.

On behalf of the working group, Health and Welfare Canada commissioned state-of-the-art research papers on the various framework cells. These papers covered the relevant literature, methodological issues, indicator requirements and research needs. Among other things, they were intended to assist the working group in generating recommendations to the department on how further framework-related research might be commissioned. Summaries of these research papers appear in Part II of this report.

5. FUTURE DIRECTIONS

The research papers in this report give us a glimpse of the work that lies ahead as we seek to ensure that health promotion assumes its proper place within our system of health care. They also hint at the vast promise of health promotion.

We need to know much more if health promotion is to become a going concern in Canada. Already we are beginning to accumulate a respectable knowledge base to support and guide our future efforts. It is vitally important that practitioners and researchers working in every setting and at every level in Canada—in communities, provinces and national organizations—take part in the effort to expand the knowledge base and to communicate what they learn to others working in the field. The invitation is open.



PART II

RESEARCH PAPERS

1. INTRODUCTION

The papers presented here illustrate the eclectic nature of the health promotion framework; their authors represent disciplines as disparate as engineering, medicine and community development. They are not intended to present a complete picture of the current state of knowledge on health promotion, since this task still lies ahead. Rather, they serve as exemplars: of the various ways in which the framework concepts can be interpreted; of the scope and range of the literature that is available; and of the possibilities for further investigation. They provide a starting point for practitioners, researchers and others to assess what we know already and to chart future moves in what is largely unexplored terrain. The Health Promotion Framework is a vision. Knowledge development will help to invest it with reality.

2. ORGANIZATION

The 25 research papers presented here were commissioned to explore the literature on various cells of the Health Promotion Framework, to identify gaps in the knowledge to date and make recommendations regarding research priorities for the future.

The reports are organized into three sections, The Challenges, The Mechanisms and The Implementation Strategies. Each section begins with a short introduction.

In some instances, the research reports presented here are summaries of longer papers. The papers which have a longer version are indicated by an asterisk on the title page. Copies of these longer versions, as well as references/bibliographies (where provided), may be obtained from:

The Health Services and Promotion Library Network
5th Floor, Jeanne Mance Building
Tunney's Pasture, Ottawa K1A 1B4

3. THE CHALLENGES

The Health Promotion Framework identifies three national health challenges that need to be met as Canada approaches the twenty-first century. They are:

- reducing inequities
- increasing prevention
- enhancing coping

Although not necessarily the only health challenges Canadians face, these three do provide an excellent starting point for research.

Prevention is a well-established concept in the health field, but the concepts of reducing inequities and enhancing coping are not at all clearly delineated. For example, there is considerable discussion surrounding the difference between inequities and social inequalities. Moreover, although we know that coping is much more than quietly enduring a difficult situation, we do not yet fully understand how to equip people to actively overcome major life crises or to manage the stress of daily hassles.

Yet, as is the case with other framework cells, the lack of a clear definition may prove to be an advantage in the research effort. To attempt a specific definition so early might be to stifle creative thinking and innovative research. At present, the challenges are so broadly stated that they accommodate a wide range of interests. There is considerable scope for interpreting and applying them to different settings, as well as for refining them and perhaps adding new challenges to the list. Within each one lies a continuum of possibilities for innovative investigation. The papers presented under the challenge headings are merely *examples* of possible research directions. They provide a small glimpse of the opportunities offered by each one.

Two researchers contribute findings and recommendations on the challenge of *reducing inequities*, each examining the links between low socio-economic status and poor health from a different perspective. Carl D'Arcy of the University of Saskatchewan proposes that efforts to reduce inequities should begin with the setting of health goals, while Havi Echenberg of the National Anti-Poverty Organization emphasizes the desirability of using a participatory approach in research aimed at eliminating socio-economic barriers to health. Both authors agree on the need to evaluate the impact on health of current social programs.

On *increasing prevention*, there are a total of 12 papers, divided into two groups. Eight of the papers focus on health areas in which the value of prevention has already been documented: alcohol and drug problems, cardiovascular disease, cancer

and mental illness. There are also four literature reviews in areas that are relatively new to the prevention domain. Jane Fulton of the Faculty of Administration at the University of Ottawa explores political and economic barriers to effective health policy in three specific cases: smoking, AIDS and the environment. Richard Stanwick of the University of Manitoba's Department of Community Health Sciences points out that modifying the environment rather than people's behaviour seems to be the most effective way of preventing injuries in children. Sylvie Jutras and Marc Renaud propose that in order to prevent growing numbers of elderly people from losing their independence, a partnership should be established between the formal and informal care networks. Making the family, rather than the individual, the target of disease-prevention programs is the focus of the paper by Ellen Rosenberg of Montreal General Hospital's Department of Family Medicine.

Only one paper examines the challenge of enhancing coping. Peter Seraganian and his colleagues from Concordia University's Department of Psychology offer a model that explains the relationship between stressors, coping resources and related health outcomes.

The reader might be forgiven for wondering about the classification of some of the research under particular challenge headings. Clearly, there are strong links among the challenges, indeed, among all of the cells of the Health Promotion Framework. For example, Dr. Jutras' paper illustrates that preventing the loss of independence among the elderly is as much an enhancing-coping challenge as it is a challenge to increase prevention. Moreover, her suggestion that there be a new partnership between the informal and the formal care networks is indicative of how the mechanisms of creating healthy environments can be employed in meeting the prevention challenge. Dr. Stanwick's paper also serves to demonstrate some of the links between these two framework cells.

These examples point to other questions. How can healthy public policy address the challenge of reducing inequities? What is the role of self-care in prevention? And what is the overlap between strengthening community health and enhancing coping? It is hoped that the papers presented in this section will stimulate research aimed not only at clarifying the nature of the framework's concepts, but also at unravelling the interrelationships among them.

REDUCING INEQUALITIES IN HEALTH: A REVIEW OF LITERATURE

Carl D'Arcy, Ph.D.

**National Health Research Scholar
Applied Research/Psychiatry
University Hospital
University of Saskatchewan
Saskatoon**

HIGHLIGHTS

- The general health status of the Canadian population has improved over the last several decades. However, although Canadians now live longer and are probably healthier, these gains have not been shared equally by all segments of the population. There remain significant socio-economic status differences in mortality, morbidity, health-related behaviours and well-being.
 - Most of these socio-economic inequalities in health cannot be explained merely in terms of risk factors, and researchers have proposed various theoretical explanations for them. Theories that emphasize the cultural and behavioural aspects of social structure appear to be the most plausible, even though they are partial and incomplete.
 - Relevant questions in assessing whether differentials in health are based on inequities are: Can the health outcome be modified? Does it start early in the individual's life-span? Does it result from factors that are outside the individual's reasonable control?
 - The literature suggests that health, like education, housing, income, etc., is a social commodity that is differentially distributed, with those at the top of the social stratification system doing much better on average than those at the bottom. Thus, social changes aimed at reducing the larger social inequalities in society will also reduce health inequalities. Improvements in the general standard of living in society will improve the overall health of its individual members.
 - Health-related behaviours are a determining factor in health and disease. Such behaviours vary according to socio-economic status, so emphasis must be on understanding the context in which such behaviours occur. Health promotion initiatives should be broadly conceived to include nutrition, good housing and other aspects of the physical and social environment that are conducive to well-being.
 - In disease prevention, areas in which substantial improvements are possible should be earmarked for action (e.g., pap smear register and reminder systems, vaccination levels). Also, new areas of initiative should be identified which tackle significant health problems and which show promise of being effective in reducing mortality and morbidity (e.g., mothers and children, adolescents).
 - Action and research should go hand in hand. As a first step, specific and measurable goals should be set for reducing health inequities in Canada. This would stimulate the development of programs and services as well as research aimed at ensuring achievement of the goals.
 - Significant social inequities exist in five health problem areas: cardiovascular disease, cancer, accidents, native Indian and Inuit health, and mental health (including addiction and dependency problems). These should be accorded priority in the goal-setting exercise.
 - Longitudinal data of all kinds is needed. Particularly recommended are: a periodic updating of the Canada Health Survey; periodic national and regional surveys on nutrition, fitness, mental health, etc.; panel studies of significant health problems; the collection of "social bookkeeping" data (e.g., statistics on mortality, nursing homes, mental health).
 - School-based health education programs (with an emphasis on nutrition, accident and exposure hazards, exercise, stress management, and mental health) should be developed, tested and evaluated for effectiveness in encouraging positive health attitudes and behaviours.
 - Research examining the effects of social policies in Canada should be encouraged (e.g., the effect of the Canada Pension Plan on health of the elderly, of unemployment insurance on the health of the workers and their families, of family allowance programs on the health of children).
 - In addition, research is needed on:
 - the dynamics of poverty and wealth and their impact on health throughout individual and family life-cycles
 - the effects of unemployment and business reversals on health
 - the prevalence and incidence of stress in various social groups, and the impact of stress on health, specifically on the immunological system
 - the interaction of work roles, family roles and gender
 - the public's perception of health and illness, particularly health attitudes, beliefs and behaviours
 - the impact of changes in the family structure on health.
-

INTRODUCTION

In his seminal paper entitled *Achieving Health for All: A Framework for Health Promotion*, given at the International Conference on Health Promotion in Ottawa, the Honourable Jake Epp, Minister of National Health and Welfare, begins by noting: "While it is true that prospects for health of the average Canadian have improved over recent decades, there nevertheless remain three major challenges which are not being addressed by current health policies and practices." (Epp, 1986) Those challenges are:

- disadvantaged groups have significantly lower life expectancy, poorer health and a higher prevalence of disability than the average Canadian
- various forms of preventable diseases and injuries continue to undermine the health and quality of life of many Canadians
- many thousands of Canadians suffer from chronic disease, disability, or various forms of emotional stress, and lack adequate community support to help them cope and live meaningful, productive and dignified lives.

There has been a renewal of interest in the topic of social inequalities in health in the last decade, particularly as a result of the debate and interest sparked by the publication in 1980 of the report of the Working Group on Inequalities in Health, convened by the Secretary of State for Social Services in England and chaired by Sir Douglas Black (The Black Report). A follow-up report, *The Health Divide: Inequalities in Health in the 1980s* (Whitehead, 1987) published by the Health Education Council, promises to continue the debate and interest in the topic.

The Black Report, particularly its accessible Penguin edition (Townsend and Davidson, 1982), attracted wide interest elsewhere in the world. Various publications on different aspects of social inequalities in health in a variety of countries have been published. However, no country appears to have attempted the comprehensive kind of review that is contained in the Black Report.

Surprisingly, the topic of social inequalities in health has generated little political or academic interest in Canada.

There do, however, seem to be at least three reasons to be interested in the topic of inequalities in health:

- A review of the patterns of health in a population and its sub-groupings encourages the process of setting objectives and establishing priorities for health care. It enables such priorities

and objectives to be grounded in fact and established in more detail.

- Inequality or inequity? Scientific explanations for inequalities in health lead to a more informed judgement as to the responsibilities for health, especially as between health care delivery and other aspects of the social environment such as housing, education, employment and work, nutrition, health behaviour, attitudes and values. Health is not just an individual responsibility; it is also an environmental responsibility.
- The measurement of inequalities provides a solid basis for judging the effectiveness of the health care system and programs in achieving health for all.

THE LITERATURE

In reviewing the literature on inequalities in health and reducing inequalities in health, we concentrated on seven broad health indicators, namely, morbidity, utilization of services, mortality, disability, information, health-related behaviours and well-being. And on seven defining social characteristics, namely, age, gender, residence (region, location, type), ethnicity, income, occupation and education.

The three defining social characteristics of income, occupation and education are considered together, under the more generic heading of socio-economic status.

With the exception of the case of native Indian populations, there is a relative paucity of data and published materials concerning inequalities in health in Canada. The general topic area has generated little interest among academics in this country. Fortunately, a larger amount of data and some limited analysis have been provided by government and public sector reports and researchers. It is apparent that Canadian data and analysis has limited opportunity to be published. Material linking health with behavioural, social and policy concerns has relatively few outlets in Canada. The publication of reports containing Canadian data is, not surprisingly, relatively rare in U.S.-based journals, which appear to be relatively parochial. Journals based in England, particularly international journals, appear to be much more likely to publish Canadian-based material.

In reviewing the material for this report, we were also struck by the paucity of data on *reducing* inequalities in health. There is a much greater variety of material on inequalities in health cross-sectionally at a particular point in time, than there is of material that looks at trends in those inequalities over time. This

lack of a longitudinal dimension in much of the literature on inequalities is not unique to Canada, but is also evident in the international literature. No doubt, it reflects the contextual constraints within which socio-health research operates.

It is difficult to obtain funding for long-term research and to maintain the necessary resources over time, especially given the sometimes long-term pay-out for the research. The longitudinal data that do exist tend to be institutionally tied to other reporting requirements. Such longitudinal health-related data rarely include information on social status (except for age, sex and, possibly, location of residence). However, some other countries appear to have more useful data sources for examining the effects of social inequalities in some health measures over time. The Americans have their National Health Interview Survey, and the British have longitudinal mortality data. These data sources can be more easily used to track changes in inequalities and health over time.

In contrast to the paucity of data on inequalities in health over time, considerably more data exists in Canada on documenting inequalities in health at a particular point in time cross-sectionally. However, the timeliness of some of the available cross-sectional data leave a lot to be desired. If one uses Canadian Health Survey data to look at inequalities in morbidity, one is using data that is 10 years old. The relationships may have changed during the last decade, either improving or deteriorating.

Given the relative lack of data and analysis of inequalities in health over time, either reducing or increasing inequalities, it is not surprising that there is little analytic literature that attempts to examine competing explanations of existing inequalities in health. Again this situation is not unique to Canada. There are a variety of testable hypotheses that can be generated from the various competing explanations of these inequalities.

Reducing Inequalities by Raising the Level of the Lowest

In terms of "reducing" inequalities one has to be cognisant of emphasis. If one is solely concerned with the "gap" between various social groupings or states, one may miss significant changes in level. One can easily conceptualize a reduction in the "gap" in health status between groups and miss the change in the overall level of health of those groups. The life expectancy gap between men and women (women currently live longer) could be reduced by women dying sooner, women dying sooner and men living a little longer, or by men living longer. In more simple terms, one can reduce inequalities by bringing the top group down, lowering the top group and the bottom raising a little, or by raising the level of the lowest group relative to the others. The emphasis, it is pre-

sumed, is and should be on reducing inequalities in health by raising the level of the lowest or most disadvantaged group.

Inequalities in health can serve one useful function by indicating what level of health is realistically attainable, given existing circumstances and technologies.

Reducing Inequalities? Some General Evidence

Mortality rates in Canada have shown a general and substantial decline. Mortality from specific categories of diseases show a more diverse pattern. Age-standardized mortality rates for cardiovascular disease (the leading cause of death in Canada) for women fell 53% between 1951 and 1981, while for men the rates dropped 38%. Age-standardized rates for cancer, the second leading cause of death in Canada, continues to increase, although there are variable patterns for specific cancers in specific segments of the population. For example, there was an 11.5% increase between 1981 and 1982 in lung cancer deaths in women.

In contrast to most other measures of health status, data on estimated life expectancies has been available for Canada and the provinces for the last six decades. Life expectancies covering shorter time periods have also been calculated for various regions and social groups in Canada.

Life expectancy is a measure of the mean length of life of a cohort assuming that the mortality pattern is stabilized at the level observed during a given period. The life expectancy measure is seen as a good indicator of the overall health level of a population. Given the longitudinal nature of the data available, these life expectancy data provide the best available summary indicator of general trends in inequalities in health in Canada.

In very general terms, when we look at life expectancy data for Canada we see a steady increase in life expectancy over the last several decades. Life expectancy at birth increased from 61.0 years in 1930-32 to 75.3 years in 1980-82. However, this general trend masks other interesting patterns. For men, life expectancy at birth increased from 58.8 years in 1920-22 to 71.9 years in 1980-82. The gain for men over the six decades was 13.04 years; for women the gain was 18.46 years. Through these decades generally women made greater gains in life expectancy than men; however, during the 1975-77 to 1980-82 time period, this general trend was reversed, with males reporting greater gains in life expectancy from birth (1.62 years) than women (1.36 years). Data on life expectancy at age 60 reveals a somewhat different picture. Life expectancy for males aged 60 went from 16.42 years in 1920-22 to 17.97 years in 1980-82 a total of 1.55 years. For women aged 60, the increase was from 17.02 years in 1920-22 to 22.93 years in 1980-82, a total of 5.91 years.

These data clearly show that the gains in life expectancy have largely been in terms of younger age groups surviving, no doubt as a result of the conquering of the traditional diseases of childhood, particularly infectious diseases. Also of interest, but less readily explainable, is the generally widening gap between males' and females' longevity. Women have generally benefited disproportionately from improvements in life expectancy, though there is some preliminary evidence that this general trend is changing. One might be tempted to explain some of these gains in terms of improved prospects for childbearing; however, one should note that the gap in life expectancy between men and women who have reached age 60 has widened and appears to continue to do so.

During the earlier part of the century, life expectancy at birth and other ages differed significantly from province to province. Since 1931, however, with few exceptions, there has been a strong trend towards the convergence of life expectancies and survival probabilities not only at birth but also at other ages. In 1931, Quebec had the lowest life expectancy for both males and females, at 56.2 and 57.7 years respectively, while the highest life expectancy for males and females was in Saskatchewan, at 64.2 and 65.9 years respectively, representing an overall difference of approximately 8 years. By 1981, the provincial difference in life expectancy had declined to 2 years. Prince Edward Island had the longest life expectancy for males and females, at 72.8 and 80.5 years respectively, while Nova Scotia had the lowest life expectancy for both sexes, at 70.9 and 78.5 years respectively.

Regional comparisons however mask *intra-regional* variations. Wilkins and Adams (1983) report substantial variations in life expectancy by size of community, with life expectancy varying directly with community size. Metropolitan areas with populations of 1 million or more were estimated to have life expectancies of 71.8 years for males and 78.8 years for females in the late 1970s. The comparable figures for rural areas and communities of less than 1,000 population were 69.1 years for males and 76.0 years for females. The data suggest substantial variations in life expectancy within the various provinces and regions of Canada. Wilkins (1986), in his analysis of health expectancy in the local community service districts of Montreal, shows life expectancy varying from 61.4 years for males and 70.9 years for females in the lower-income working area of St-Henry/Little Burgundy, to 72.2 years and 78.2 years for males and females respectively in the upper-income university-educated area of Notre-Dame-de-Grace East/Westmount.

Data on life expectancy for various socio-economic groups shows some encouraging and some discouraging patterns. Life expectancy by income quintile for metropolitan Canada in 1971 was reported to be 72.47 years for males in the

highest income quintile (H), and 66.33 years for those in the lowest income category (L). The comparable 1971 figures for females were (H) 77.45 years and (L) 74.62 years. The same life expectancy estimates for 1984 are (H) 75.36 years and (L) 69.71 years for males. For females, the 1984 figures are (H) 81.00 years and (L) 78.59 years. It should be noted that gender differences in life expectancy are greatest in the lowest income quintile. In general, there appears to have been some reduction in the inequality in life expectancy between the highest and lowest income groups during the 1971-84 time period. For males, the average gain in life expectancy from birth has been 3.05 years, with greater gains being registered by the lowest income quintile (3.38 years, in contrast to gains of 2.89 years in the highest income quintile). For females, the average gains were 3.70 years, with similar greater gains in the lowest income quintile (3.97 years, in contrast to gains of 3.55 years in the highest income quintile). However, if we look at gains in life expectancy at age 60, greater gains are recorded in the highest income quintiles than in the lowest income quintiles: gains of 2.03 and 2.87 years for males and females in the highest income group, and gains of 1.83 and 2.83 years in the lowest income group.

Data are scarce on health conditions of various ethnic, racial and cultural groups, with the exception of status Indians. In some respects there is overlap between such groupings and other measures of social and economic status. Comparisons of life expectancy between Indian and non-Indian are not very encouraging in terms of reducing inequalities in health. Although average life expectancy at birth for both Indians and the national population has improved, the discrepancy in life expectancy has largely remained unchanged or increased. In 1961, 1971 and 1981, the life expectancies at birth for male Indians were 59.7, 60.2 and 62.4 years some 8.8, 9.1 and 9.5 fewer years of life expectancy than the national population. For female Indians, life expectancies were 63.4, 66.2, and 68.9 in 1961, 1971 and 1981 respectively. Thus, female Indians had 10.8, 10.1 and 10.0 fewer years of life expectancy in 1961, 1971 and 1981.

Cross-sectional data on morbidity episodes, the utilization of services, mortality, disability, health information and knowledge, health related behaviours, and general well-being show that significant inequalities in health currently exist in Canada. These inequalities in health between various social groupings do not appear to have greatly diminished over time.

Socio-economic status variables, in addition to the demographic variables of age and gender, emerge as dominant defining social characteristics that affect health status. Socio-economic status

substantially modifies the effects of demographic variables on health.

Significant socio-economic gradients are also evident in Canada in the major categories of diseases and injury, including cardiovascular disease, cancer and accidents (the three leading causes of death in Canada) and mental disorders (a leading cause of hospital day use).

The social inequalities in health are not unique to Canada, but characterize industrialized societies to greater or lesser degrees.

International comparisons suggest, however, that with respect to a variety of specific health problems, Canada could indeed improve its health performance.

The general picture that emerges from reviewing the data and literature on reducing inequalities in health is that the general health status of the Canadian population has improved during the last several decades. Canadians live longer and are probably healthier. However, these gains have not been shared equally by all segments of the population. The health of the disadvantaged has not improved relative to that of the advantaged in Canada.

These significant social inequalities in health in Canada affect the quality and length of individuals' lives. The evidence clearly suggests that there is no insurmountable reason for their existence. They can be reduced. For Canadians there can be greater health equity and improved health for all.

Sources of Health

When confronted with the fact that there are inequalities in health, the average Canadian is perplexed. Don't we have medical care and hospital insurance programs? Everybody, more or less, has access to good quality medical care. So why should there be inequalities in health? Isn't that what comprehensive public medical and hospital programs were all about ensuring access to care and thus decreasing inequalities in health?

Of course, medical and hospital care are in reality part of the "sick" (as opposed to "health") care system. By and large, they do little to promote the health and general well-being of the population. They generally deal with people who have become "un-healthy".

Health comes from a variety of sources:

- genetic—basic physical endowment;
- environment—the physical and psycho-social environments (including environments positive for growth and development, hazards, exposures to noxious elements);
- services (access to services that can correct, cure, stabilize, prevent health problems).

Health does not just occur at one point in life. It occurs through time as various experiences

throughout the life-span are connected. The human individual is more vulnerable to the negative effects of physical and psycho-social insults during specific points in the developmental process. Insults early in life are more significant for health and psycho-social development than similar insults later in life.

Health does not come solely, or even largely, from the "sickness" care delivery system. The Ottawa Charter for Health Promotion lists peace, shelter, education, food, income, a stable ecosystem, sustainable resources, social justice and equity as the prerequisites for health.

It is obvious that such prerequisites for health are much more likely to be differentially socially distributed.

Explaining the Inequalities and Inequities

A variety of loosely structured theories have been offered in an attempt to explain these persistent inequalities in health.

These theoretical approaches can be grouped under the general headings of:

- artifact
- natural and social selection
- materialistic and structural factors
- cultural and behavioural factors

Explanations based on the artifact theory suggest that there are no causal relationships between defining social characteristics and health, and that the data on these variables just come together, accidentally. However, the consistency and replicability of the findings, both over time and across jurisdictions using a variety of operational measures, argues for the dismissal of such arguments as being basically implausible.

In general, explanations based on the natural and social selection argument hold that physical strength, vigour and mental and physical ability are integral parts of the selective social sorting process. They are integral parts of the social stratification and differentiation system in any society. The relationship between socio-economic status and health is to be expected. Some go further and argue that this is the way it should be. The bright and healthy are at the top because they inevitably rise to the top, and their skills and attitudes are required at the top. The converse is also the case.

Materialistic and structural explanations emphasize the influence on health and life chances of the material aspects of social structure. Material factors include such variables as housing, nutrition, immediate physical environment, etc. Differentials in the distribution of these goods in society are seen to account for variations in health status among various social groups.

Cultural and behavioural explanations emphasize the less material aspects of social structure,

such as values, attitudes and priorities. One might also include such factors as information, networks, and social supports under this category. Social differences in health-protective behaviour would be explained in terms of how different social groups value health, the connections they see between discrete immediate acts and the longer-term more global objective of health, the awareness of information, the willingness to make use of such information, etc.

It has been suggested (Blane 1985) that these last two types of explanation can be melded together. The argument would be that material and structural factors influence and are, in turn, influenced by cultural and behavioural factors.

Relatively few studies have attempted to assess the validity of these competing explanations. Blane (1985) specifies some of the testable hypotheses that derive from such theoretical stances. Some British researchers have attempted to estimate the effects of "social selection" on socio-economic inequalities in health (Stern, 1983; Wadsworth, 1986; Wilkinson, 1986; Power, 1986; Fox et al., 1986). Whitehead (1987) sums up the evidence on social selection giving rise to health inequalities by noting that "... there is some new evidence that health selection operates at younger ages, and new evidence for men over 50 that no such selection effect is evident after this age. Estimates of the size of the selection effect suggest that it accounts for only a small proportion of the overall differential between social classes."

A Note on "Risk Factors"

On the surface, the epidemiologic notion of "risk factors" associated with mortality may be thought to provide the explanation for socio-economic differentials in morbidity and mortality. Researchers have noted the higher occurrence of negative health-related behaviours in the lower socio-economic groups. Miller and Wigle, using Canada Health Survey data, show that there is a higher prevalence of cigarette smoking, overweight, obesity, elevated diastolic blood pressure, physical inactivity, excessive alcohol consumption, elevated serum cholesterol, diabetes and the co-joint use of oral contraceptives and cigarettes among men and women with a low level of education. These variables are "risk factors" that are significantly associated with cardiovascular disease. The authors note that these study results are "... consistent with those of recent Canadian studies showing that both men and women in lower socio-economic groups are more likely to die from cardiovascular disease." (p. 127)

The Alameda County (California) studies have been instrumental in the "risk factor" approach. Prospective studies from the Alameda data set suggest that the differential distribution of risk factors

accounts for approximately 50% of the excess deaths in the lower socio-economic groups.

A ten-year follow-up of the Nutrition Canada Survey sample showed that cigarette smoking, hypertension and diabetes were factors associated with a significantly increased risk of death. The population attributable risks for smoking, hypertension and diabetes were 39%, 8% and 6% respectively for men, and 21%, 12% and 7% for women (Johansen et al., 1987). However, additional analyses for an eleven-year follow-up of that same sample, looking at the effects of income and risk factors, shows that after controlling for the effects of the risk factors of smoking, blood pressure, diabetes and cholesterol, there was a significant income effect. This effect was most pronounced for the lowest income category, more pronounced for females than for males, and more pronounced for cardiovascular deaths than for deaths from all causes.

The fact that risk factors do not explain away most of the socio-economic status differentials in health should not be surprising. There is no guarantee that the risk factors considered are all the relevant ones that affect health. The measurement of the risk factors themselves is subject to error and may be in need of substantial refinement. Socio-economic status is not a "one-time thing". An individual's economic fortunes may fluctuate over time. Indeed, these fluctuations in economic well-being may correspond to life and family cycle stages. In keeping with the notion of a life-span, the effects of poverty upon health may be greater during certain periods of the developmental process. Forsdahl's (1977) study of the occurrence of heart disease in the counties of Norway suggests "... that great poverty in childhood and adolescence, followed by prosperity, is a risk factor for arteriosclerotic heart disease."

Perhaps the most important point to make with regard to risk factors is that *it is not sufficient* to conclude that the differential distribution of risk factors provides part or most of the explanation of socio-economic differentials in health. Attention must be directed to the reasons for socio-economic differentials in health-related behaviours (e.g., cigarette smoking, obesity, leisure-time physical activity) and what can be done about them.

Berkman (1986) points out that if socio-environmental conditions influence physical health they must do so through some biological pathway. If these socio-environmental conditions function, in part, by altering risk factors, it would be a mistake to treat such risk factors as simple confounders rather than as potential mediators or pathways leading from a social experience to a health outcome.

Some researchers attempt to explain the residual link between socio-economic status and health (after

taking into account risk factors) in terms of stress and its impact on the susceptibility of the organism to insults. There is a growing body of literature which links social and psychological stress to reduced functioning of the immune system. This nervous system-immune system linkage provides an additional plausible biological mechanism of action linking psycho-social stressors, especially those stresses differentially associated with social class position, with physical and mental health conditions.

COMMENT

Of the various theoretical approaches, those explanations that emphasize the material and non-material (cultural and behavioural) aspects of social structure appear to be the most plausible for providing an understanding of the origins and persistence of social inequalities in health.

It is important to recognize that illness is also a social and psychological process, and not just a physical or medical phenomenon. Illness, illness behaviour and disease are the products of the interaction of both lay and professional constructions of illness (Friedson, 1970). The lay construction of illness depends on how individuals and groups view the signs and symptoms of illness, how they react to them, their help-seeking behaviours, and their experiences with those symptoms, etc. The professional construction of illness depends on who is empowered to treat, the educational process and formal stereotypes, organization and structure of the delivery system, etc.

Also important is the cumulative nature of life experiences, the notion of a life-span in which experiences in earlier stages of life affect the development of, and reaction and response to, symptoms in later life.

Socially descriptive categories, or variables such as age, gender, socio-economic status, etc., are, in fact, shorthand for constellations of factors that involve:

- *experiences*—physical, social and psychological
- *attitudes and values*—perception of choices, readiness and willingness to take action, etc.
- *resources*—material, psychological and social

In essence, when we are talking of or describing social groups, we are referring to individuals and groups who: have had different experiences (both physical and social-psychological); have differential access to resources (both physical and social); and have developed different attitudes and values. These, in turn, lead to different experiences. Particular constellations of experiences, values and re-

sources may be more or less favourable to positive health outcomes.

Theories that seek to explain social inequalities in health have to take into account these differentials in experiences, resources, and attitudes and values and their effects throughout the life-span. These theories will also have to integrate reactions or responses to the symptoms of "illness" the notions of lay and professional constructions of illness.

Inequalities and/or Inequities?

Not surprisingly, there is some ambiguity in the literature as to whether the social differences in health documented here are *inequalities* (that is, uneven, but implying no judgement as to "rightness" of this unevenness) or *inequities* (that is, unevenness that is unjust, that is a result of bias and unfairness). Inequalities may be noted. Inequities call for social and political action.

There are three criteria that should be used in judging whether social differences in health are inequities or inequalities. First, can the health outcome be modified? To a large extent, this is a function of our existing knowledge; however, the very fact that the health outcome is differentially distributed socially implies that it is, in principle, amenable to modification. Secondly, it can be argued that social inequalities which start early in the individual's life-span are not merely inequalities, but are, in fact, inequities a result of the unfairness or bias in the social stratification system. Furthermore, health differentials early in life not only affect one's immediate health but may also affect the developmental process and the acquisition of other relevant skills essential or useful to "success" in later life (e.g., schooling). Inequalities that start early in life are circumstances or events over which the developing human individual has no control. The data for Canada do indeed show significant social inequities in terms of peri- and neo-natal mortality and morbidity. These social inequities also persist through childhood. Currently available evidence would suggest that with respect to life expectancy at birth, significant inequities exist; however, there has been some reduction in the magnitude of these inequities during the last decades.

Thirdly, inequalities in health can be perceived as inequities insofar as they result from factors that are outside the reasonable control of the individual. For example, consider mortality-as-associated risk factors. These risk factors are differentially distributed socially, with higher prevalence among the lower socio-economic groups. It is argued here that these risk factors are themselves inequities if:

1. relevant information and comprehension concerning potential risk factors is similarly socially differentially distributed;

2. there is a differential cost attached to the avoidance of the risk factor(s) (e.g., is a high-fat diet cheaper and more accessible than a low-fat balanced diet in various areas of Canada?);
3. the risk factors and associated behaviours provide positive reinforcement for the individuals involved (e.g., does cigarette smoking reduce stress?).

There is sufficient evidence to suggest that health information is differentially distributed socially, and that there are increased economic and social costs associated with pursuing healthy lifestyles. In this sense, then, risk factors are inequitably distributed and the resulting health inequalities observed are indeed inequities.

IMPLICATIONS FOR PRIORITY SETTING

There are two general sets of implications that arise from the data documenting inequalities and inequities in health.

The first set of implications evident is that health is a social commodity, much like any other social commodity such as education, income, housing, etc. It is differentially distributed. Some people get more of it, some less. Those at the top of the social stratification system do much better on average than those on the bottom.

We would suggest that social changes that reduce the larger social inequalities in society will also reduce health inequalities. Changes that improve the general standard of living in society will improve the overall health of individual members of that society.

The second set of general implications are of a narrower focus. They relate more specifically to health (sickness) care issues.

The fact that publicly-accessible comprehensive health care (both medical and hospital) programs have not eradicated inequalities in health suggests first that "health" does not solely emanate from the sickness care delivery system. It is much more broadly based than that. Secondly, it suggests that there are limits to "access-to-services" solutions. More access to the health care delivery system will not necessarily reduce social inequalities in health. We need to look beyond traditional service-delivery and access-to-service solutions in order to improve the health status of the whole population as well as its constituent parts.

The data reviewed earlier in this paper show that there are significant social inequalities in the practice of health-protective behaviours. These behaviours are felt to have significant impact on health and disease. The areas of health-protective

behaviours, health promotion and disease prevention, generally fall outside the purview of the traditional sickness care delivery system.

Others have more eloquently documented the importance of traditional sanitation and public health measures in reducing mortality and improving health during the late nineteenth and early twentieth century (McKeown, 1976). It is suggested that our major illness problems today are of a chronic illness and disability nature rather than the result of acute infectious diseases (Fries, 1983). New strategies have to be developed to meet these changed circumstances.

More emphasis needs to be placed on health promotion and disease prevention. However, in pursuing such a strategy, the emphasis must be away from a "blame-the-victim" approach and towards an approach that attempts to understand the context in which negative health-related behaviour occurs. The emphasis must be on understanding the incentive structure and the positively reinforcing elements of the illness-producing behaviours with a view to getting the leverage necessary to effect change in that behaviour.

In terms of illness prevention, we need to first look at the range of illness prevention activities routinely engaged in, and earmark for action those areas in which substantial improvements can be made, e.g., the provision of adequate sewer and water systems in native communities, vaccination levels, adherence to diabetic diet treatment regimens, pap smear register and reminder systems, adolescent smoking.

Secondly, we must identify new areas of initiative which tackle significant health problems and show promise of being effective in reducing mortality and morbidity. Initiatives for mothers and children, and adolescents are suggested.

Thirdly, health promotion activities should be broadly conceived to include nutrition, good housing, and other aspects of the physical and social environment that are conducive to well-being.

RECOMMENDATIONS

Action and Research

It is apparent to this reviewer that the need for more definitive research need not, indeed should not, precede taking action to reduce inequities in health in Canada. We know enough now to be able to recommend specific actions to deal with some of the glaring inequities in health in Canada.

Action and research should not be seen as antithetical to one another, but rather go hand in hand.

Health Goals for Canada—A Framework for Action and Research

The most significant action that could be taken to stimulate both action and research in terms of reducing social inequities in health would be to promulgate a set of specific and measurable health goals for Canada for reducing inequities.

Goals should also be set for the two other major health challenges facing Canada—those of increasing prevention and enhanced coping. The setting of national health goals should also encourage those provinces that have not already done so to identify health goals for themselves.

Setting measurable and specific health goals would first stimulate the development of programs and services aimed at achieving these goals. There would be a heightened utilization of existing knowledge. Secondly, the existence of target health goals would stimulate and guide research aimed at ensuring the achievement of those goals and at assessing the effectiveness of programs, services and specific techniques in achieving those goals.

The exercise of setting health goals would heighten the profile of inequities and inequalities in health among Canadians. Setting health goals, indicating what is unacceptable and what is desirable, is a prerequisite to stimulating and guiding health research towards achieving such goals, and towards reducing inequities in health in Canada.

Some Specifics

- As part of the initial process of setting health goals to reduce inequities in health, we should initially address five health-problem areas. There is evidence indicating that significant social inequities exist in these areas, and we have the tools and knowledge to begin to do a much better job and so have a significant impact in reducing inequities in health in Canada. These priority health-problem areas are:
 - cardiovascular disease
 - cancer
 - accidents
 - native Indian and Inuit health
 - mental health (including addiction and dependency problems)

The objective is to encourage action and research in these priority areas.

These health-problem areas should be seen as priority areas for action and research aimed at reducing inequalities and inequities in health.

- The largest deficit in terms of examining the issue of reducing inequalities and inequities in health is the lack of

longitudinal data on the major social and health dimensions examined. In the absence of data on relevant health and social variables, it is very difficult to look at changes and the impact of programs and policies over time. These longitudinal data need to be elicited using both cross-sectional repeated measures and panel designs. In view of the relative scarcity of this type of data, almost any type of data with a longitudinal dimension would be welcome. In particular, a periodic updating of the Canada Health Survey would be greatly welcomed, as well as periodic national and regional nutrition, fitness, mental health, etc., surveys.

There is a need to encourage panel studies of significant health problems so as to get a much better picture of the course and outcome of diseases, their impact upon an individual's life and the impact of interventions on their course and outcome.

Under this general heading, there is also a need to stress the importance of collecting, analyzing and publishing on a continuous basis good-quality national "social bookkeeping" data as applied to health, e.g., mortality statistics, nursing home statistics, mental health statistics.

- It is suggested that children, and, by implication, the mothers of young children, should be targeted as a specific sub-group of the population that could be very profitably exposed to increased health promotion and disease prevention efforts. Mothers are largely responsible for the health of children. They are central to the initiation of new, positive, health-protective behaviours in the next generation. Positive health practices and illness prevention efforts started early in life are more likely to "stick". They can also influence health and health behaviours during the early and formative years of life. Early implementation in the life-span enhances the potential of protective health practices having positive impact and payoff.

It is noted here that young families in Canada are most likely to have low incomes. The proportion of children living in families with low incomes has increased during the 1980s. Approximately one in five children in Canada currently lives in a low-income family—1.1 million children in Canada in 1985 were in low-income families (Methot, 1986; Arnot, 1986). The emphasis should be on minimiz-

ing the negative impact of poverty on health as those children grow into adulthood.

- School-based health education programs should be developed, tested and evaluated for their effectiveness in encouraging positive health attitudes and behaviours. Emphasis in these programs should be on nutrition, accident and exposure hazards, exercise, stress management and mental health.
- Despite the tremendous volume of data linking poverty to ill health and the wide variety of programs and policies aimed at reducing poverty, few, if any, studies have looked at the effects of these programs and policies. The one experiment in Canada with a guaranteed minimum income plan in Canada (The Manitoba Mincome Study) did not include any measures on health status. Research that examines the effects of social policies on health should be encouraged. What has been the effects of the Canada Pension Plan on the health of the elderly? What are the effects of unemployment insurance upon the health of the individual worker and his or her immediate family? What is, and has been, the effect of family allowance programs upon the health of children?
- The dynamics of poverty and wealth and their impact upon health during the life-cycles of individuals and families need to be examined.
- More detailed longitudinal studies are needed to look at the effects of unemployment and business reversals on health. The moderating or amplifying effects of joint family incomes, age, gender, and the cyclical or episodic nature of the unemployment experience need to be examined.
- The impact of stress upon the immunological system is an exciting area of research, with significant potential for the issues of inequalities and the reduction of inequalities in health.

Research in this area should be encouraged.

- Research that looks at other possible mechanisms of action in terms of the prevalence and incidence of stress in various social groups, and the impact of stress upon health, needs to be funded.
- Research on the interaction of work roles, family roles and gender also needs to be encouraged.
- Research on the public's perception of health and illness is needed, particularly research on health attitudes, beliefs and behaviours. With the growth of an aging population and the increased prevalence of non-fatal chronic health problems, quality-of-life issues will become more important. How health is defined and reacted to will assume greater importance.
- More fundamental research is needed on the relationship between health attitudes, beliefs, information and behaviours.
- The Canadian family structure is changing; research is needed to look at the possible health impact of these changes.
- The need for a much better forum for the dissemination of relevant Canadian studies and experiences is needed. It is suggested that a multi- and inter-disciplinary Canadian journal *Health, Behaviour and Policy* be established to facilitate the exchange of information across the country.

The formulation of health goals for Canada would provide a framework for structuring both action and research. The specific initiatives suggested are illustrative, and encompass fundamental, applied and evaluative research and action. We need to apply what we already know. We also need to know more, so that we can provide reasonable and ethically acceptable solutions to health and social problems. The motive of these recommendations is to encourage both action and research to reduce inequalities in health in Canada, and to achieve not only health for all, but better health for all.

REDUCING INEQUALITIES*

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* Summary version

HIGHLIGHTS

- Low income and poor health are inextricably linked, and reducing health inequities necessarily implies acting to remove health barriers caused by poverty.
 - The three main conditions resulting from poverty which contribute to poor health are hunger/malnutrition, unhealthy environments, and stress.
 - Health inequities are also related to the design of service and program delivery mechanisms, the attitudes of those involved in the design and delivery of programs and services, and contradictory government policies that create or contribute to health barriers.
 - Policy-makers should consider fully the impact of health programs on disadvantaged groups. In particular, the impact of existing programs should be assessed before new ones are developed. There is a need to study the interrelationships among different sets of information collected by government (amount of funds spent, types of programs, types of users, morbidity and mortality statistics), and to try to use this information more effectively, so that the level of resources committed to health bears a direct relationship to the results achieved.
 - In trying to determine what works and what does not, what people need and how they need it, policy-makers should tap into the accumulated experience and expertise of communities. In particular, those who are disadvantaged and "barred from health" are best placed to know what their own needs are and what methods of delivery will be effective.
 - Researchers must find ways of collecting data on which programs and policies are genuinely effective in eliminating barriers to equity in both health care and health opportunities.
 - Current data collection focuses on "inputs" to the health system, such as the number of doctors, the availability of hospital beds, hospital admissions, etc. Such data must be complemented by data from surveys of both users and non-users of the health care system—their opinions, the results of their interaction with the system, the complaints for which they are likely to seek treatment, etc. Also needed is demographic information on these groups (e.g., household structure, employment status, sex, ethnicity, adequacy of shelter, parenting responsibilities, source and level of income, degree of isolation/distance from services, etc.)
 - Studies must be conducted into the cost-effectiveness of allocating increasing amounts of funds to increasingly costly technology.
 - Data is needed on stress as a health indicator, including the sources of such stress.
 - Community organizations may lack a sophisticated knowledge of the policy process, and the ability to document their own experience. There is thus a need for participatory research aimed at identifying health inequities and devising strategies to overcome them so that disadvantaged groups can have access to health services and programs. Such participatory research should include personal one-on-one dialogue with the members of such groups.
 - It is important to build on successes. This means providing funding for pilot projects on services and programs known to be effective in meeting the health needs of disadvantaged groups. It also means ensuring that funding for the models developed and for promoting communication among different community-based groups involved in the delivery of health services, is readily and promptly available. Energy that might be spent on removing barriers should not have to be diverted into securing funding.
 - A cost-benefit analysis of the existing system should be carried out, taking into account revenues from fees, total service costs and health costs. This would help in determining whether real economies are being achieved by user fees, excluding dental care from *Canada Health Act* services, etc.
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INTRODUCTION

The National Anti-Poverty Organization (NAPO), founded in 1971 to provide an effective voice for low-income Canadians on national issues, welcomed the call for proposals for literature reviews on areas identified in *Achieving Health for All: A Framework for Health Promotion*. Over the years, NAPO has argued consistently that low-income Canadians, the organizations they form, and the agencies that work for and with them have a valuable, perhaps vital, role to play in formulating policy, and in developing instruments of policy intended to alleviate or address their problems. Hence, we proposed a review of community-based literature on health inequities.

Because NAPO's Board of Directors consists mostly of individuals who are or have been poor, and because this Board consistently identifies health services as a priority for research and advocacy, we anticipated and received a positive response to our call for submissions of community-based literature. What we did not anticipate were the common themes running through the responses, since the organizations varied from quite policy-sophisticated bodies, such as social planning councils, through health-policy-specific coalitions, to welfare rights organizations. Regardless of the source, almost all submissions focused on inequities in occurrence and treatment of illness, and inadequacies in the health services delivery systems, to the virtual exclusion of considerations relating to inequity in the conception and implementation of prevention and promotion efforts, or perceived injustice in the policies underpinning the health care system.

The surprising consensus of opinion, combined with the non-academic nature of the literature reviewed, has encouraged us to synthesize our review, to identify gaps in knowledge, to propose priority questions for further research, to postulate political and social considerations, and to suggest implications for action. The same two considerations preclude detailed comment from us on methodological considerations, suggested indicators and data needs.

SYNTHESIS OF LITERATURE REVIEW

NAPO culled community-based literature from our own documentation centre holdings, from our Board members, from a call to all our group members (almost 200 across Canada), through a memo distributed with our newsletter, and through follow-up telephone calls, from social policy groups within the Social Policy Reform Group and within the mailing list of the Canadian Council on Social

Development, and from health policy and service groups listed in community and social services directories available to us. Almost 70 groups responded, representing a wide range of organizations in terms of size, geographic location, primary mandate and level of policy sophistication.

None of the documents challenged the fundamental and inextricable link between low income on the one hand and higher mortality and morbidity rates on the other. Therefore, they concentrated on describing and documenting anecdotally the human face of that link. Almost all groups dealt with the inequities created by conditions of poverty, with a broad interest in three general symptoms: hunger/malnutrition, unhealthy environments and stress.

Hunger/malnutrition was the most flagrant symptom of both poverty and health inequity. Documents focused on income inadequacy as the main factor leading to hunger and malnutrition. Social policy, health policy, and human services delivery agencies have repeatedly documented the fact that the money required to provide nutritious and health-building meals is not available to individuals and families who rely on social assistance, social insurance, minimum-wage or part-time work, or disability or elderly benefits. While this inadequacy has been a historical fact, the recent emergence of food banks and the exponential increases in demands placed upon them are evidence that things are getting worse, not better.

Many documents and organizations expressed great frustration with the lack of recognition and acknowledgement of the severity of the problem. School teachers have taken an increasingly active role in trying to find solutions, as they daily confront hungry and undernourished children, and as they witness the effects of these health deficiencies on their learning.

Efforts to find the root of the explosion of hunger in many cities have led groups to document unhealthy atmospheres as part of the income inadequacy contribution to health inequity, as increasing rents for decreasing quality of shelter are the least postponable expenses. In its own way, the rising cost of shelter, without any offsetting increase in income, contributes to hunger and malnutrition, but the shelter of Canada's poor contributes to health inequity in other, more direct ways.

Even housing that is far too expensive for poor Canadians is usually badly heated and ventilated, often too small, and located in neighbourhoods with greater risks of traffic accidents, environmental pollution, accidents resulting from inadequate recreation space, and often relatively high crime rates. As well, for those low-income Canadians who earn wages, the work environment is more likely to be hazardous to health.

However, the greatest contributor to health inequity among poverty's symptoms identified in the literature was stress: the stress of knowing that every visit to a social worker, doctor, or employment counsellor could result in a reduction in the amount of or an end to the regular cheques; the stress resulting from being a sole-support parent; the stress of having to choose between paying rent and buying medicine, or between warm clothes and food for the children. There can be little doubt that these stresses contribute to ill health, which itself is an additional and overwhelming stress.

Certain groups identified particular stresses to which they were subject, as well as service delivery and particular attitudinal factors, as contributing to health inequities among their members or constituents. These groups included disabled people, especially disabled women; farmers; residents of rural or otherwise isolated communities; and seniors. These groups have documented eloquently their own barriers to health, and their expertise is especially evident in their analyses.

Other common, but not universal, health inequities identified were those resulting from the actual design of delivery mechanisms, those resulting from the attitudes of those who design and deliver the services, and those resulting from government policies that intentionally or inadvertently create or contribute to barriers to health equity. Because they were identified more selectively, it is more difficult to offer a generalized synthesis of these findings. However, in the case of both delivery mechanisms and attitudes, the literature describes the expectations placed on health care consumers that those from low-income and otherwise disadvantaged environments often cannot meet. These include user fees; uninsured services; the cost of prescription drugs and of transportation to and from health care facilities; the ability to read and understand directions and instructions geared to a well-educated, middle-class patient; the ability to understand both the language and cultural contexts of the dominant cultural groups; and the ability to pursue ancillary services. Consequently, many low-income Canadians make limited use of the health care system until their health problems are acute, resulting in late detection of illness and a curative rather than preventive approach.

On the issue of conflicting policies, the literature points to conflicts between levels of governments, e.g., municipal governments cutting recreation programs just as health practitioners are promoting physical activity, or provincial governments cutting health spending as the federal government promotes prevention, or the federal government passing legislation (Bill C-22) that will likely increase the cost of prescription drugs, just as provincial governments begin to introduce or increase the

contributory requirement in existing drug plans. Even at the federal level, groups pointed to the *Health for All* activity as being contradictory to Bill C-22, and a lackadaisical approach to environmental issues as being contrary to healthy policy.

GAPS IN KNOWLEDGE

While few documents were scientific in approach, many questioned whether policy makers had fully considered the impact of various health programs on disadvantaged groups. They challenged program designers to test the impact of existing programs prior to developing and implementing new ones.

The overwhelming, although largely unarticulated, sense of community groups is that government does not know what works and what does not, at least for people who are unlike those designing the programs. Put differently, government has data on how much money is spent on which programs, some information on who uses which programs, considerable demographic information on who in any community is most likely to need which health services, and detailed data on morbidity and mortality among those same groups. What seems to be missing are the interrelationships amongst all of these. If we know what goes into the health system, and we know what comes out, why don't we know how to make one influence the other?

Although community groups were able to identify in their literature what does not work, only a few were able to document what does work. The literature hints that more groups know what works, but that their knowledge may be based on intuition and accumulated experience, rather than on carefully gathered statistics. If the goal is to remove barriers, those currently barred from health are the ones likely to know what they need and how they need it. In developing future policy initiatives in community health services, self-care and mutual aid, this wisdom must be tapped, so that such initiatives build on existing strength and expertise. This is particularly necessary in the case of disadvantaged groups, whose needs and methods are different from those of groups who have not faced barriers in the past.

METHODOLOGICAL CONSIDERATIONS

NAPO, with its relatively extensive network of individuals and groups who are on the wrong side of those barriers, correctly anticipated that those organizations and individuals most familiar with health inequities would be the least likely to document their experience or their views. Those least sophisticated in and familiar with policy develop-

ment and analysis failed to contribute literature to this study. There is little doubt that such literature exists, and it is almost certain that a wisdom on the issues has evolved, but a call for materials and subsequent telephone calls were insufficient to tap this sector.

Similarly, community-based non-policy groups and service delivery agencies not staffed by professionals provided only limited materials. Where groups had developed expertise in any aspect of health policy or services, they were quick to respond. However, again, we have not fully exploited the information, expertise and wisdom that exists.

Our search for literature was profitable in two sectors: policy and delivery agencies specializing in health issues, and policy and delivery groups with non-health-specific mandates but staffed by professionals. This material is rigorous, thoughtful and illuminating, and may be the most compatible with the scholarly research.

SUGGESTED INDICATORS

While this is clearly best left to the experts, ways must be found to collect data on which programs and policies are genuinely effective in eliminating barriers to equity in health care and health opportunities.

NEED FOR DATA

Current data collection focuses on "inputs" to the health system, e.g., the number of doctors, the number of hospital beds, the number of hospital stays. There must be a more consistent and frequent survey of the users of the system, and of non-users, with an effort to determine not only how they feel, what they notice as results of medical treatment, and whether they seek treatment for "minor" complaints, but also the demographic variables that are known to impact on health, including household structure, employment status, adequacy of shelter, parenting responsibilities, source and level of income, and gender.

Also, as increasing financial resources are allocated to increasingly costly technology, some data on the cost-effectiveness of this approach are needed.

PRIORITY QUESTIONS FOR RESEARCH

Community-based organizations have identified the need to collect data on such demographic fac-

tors as ethnicity, nature of shelter, source of income, degree of isolation/distance from services, and on stress as a health indicator, including the source of such stress.

There is a clear and demonstrated need for participatory research on health inequities, so that community organizations which lack policy sophistication and the infrastructure to be able to document their experience can be involved in identifying barriers and ways to overcome them. Their wisdom can also contribute enormously to the design of research and programs so that the findings will be more relevant to those groups that are most systematically barred from access to health services and programs. Traditional means of eliciting the wisdom of these groups have not achieved results; personal, one-on-one dialogues would draw out the wisdom, and must be the nature of the research.

Where services and programs are described as being successful in meeting the health needs of disadvantaged groups (as some have been in the literature reviewed here), funding for similar pilot projects and secure funding for the models developed must be provided promptly and easily. Where solutions have been found to the existing barriers, the provider of the solutions should be freed to do that work, and should not have to divert energy to secure funding.

In too many cases, local groups are forced to reinvent the wheel because they do not know about programs that are working elsewhere. This points to a need for greater communication among community-based groups involved in delivering health services. Again, funding for such exchange should be provided easily, so that energy does not have to be diverted from service delivery. Pilot project funding, experimental funding and funding for increased communication must all be seen as economies within the health delivery system, since they start with successes rather than devoting dollars to developing the same solutions again and again, each in isolation.

Considerable thought must be given to whether real economies are achieved from user fees, incomplete service insurance, the exclusion of dental care from *Canada Health Act* services, and reliance on distinct social service delivery systems to offset health-related costs. A cost-benefit analysis, taking into account revenues from fees, total service costs and health costs would be useful in setting future policy directions.

INCREASING PREVENTION: SOME ECONOMIC AND POLITICAL CONSTRAINTS*

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* Summary version

HIGHLIGHTS

- To ease the implementation of healthy public policy and improve its coordination, the nature and operation of economic and political barriers to these processes must be understood, as well as the instruments that government can use to implement such policy. These questions are examined with reference to three policy areas: smoking, AIDS and acid rain.
 - The literature on health risks points to the need for further research on: causal links between risks and disease; identification of vulnerable groups; and the effects of increased prevention and health promotion initiatives on health outcomes.
 - Criteria need to be established for the development of healthy public policy. Research is also needed to explore the mechanisms by which a healthy "first-generation" public policy implemented by one government department can bring forth a healthy "second-generation" policy response from another.
 - Measures need to be developed that express the benefits of health promotion in relation to its social costs (i.e., effectiveness measures, rather than dollar outcomes). Indicators should include the numbers likely to benefit, the extent of the risk on which the health promotion strategy is focused, and the potential negative health effects of the risk.
 - Research studies are needed to identify the characteristics of various interest groups in Canada, as well as their points of influence on the policy process. An appropriate healthy public policy role should be identified for such groups.
 - Disputes and lack of coordination among government departments act as political constraints on the achievement of healthy public policy. Research is needed to identify both the causes and the incentives required to alter such behaviour.
 - Research on economic constraints should be coordinated with work on governing instruments and with research on the factors contributing to the economic power of interest groups in Canada, particularly those industries whose products/processes pose health risks.
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INTRODUCTION

The expedient introduction of public policy, whether health promotion or other, may be facilitated by an analysis of barriers to its implementation. This study accepts two tasks whose goal is essentially improving the coordination and implementation of healthy public policy. The first task is to identify economic and political barriers, and the second is to explore these barriers in three separate policy areas or cases: smoking policy, AIDS policy and acid rain policy. These two efforts are linked together by exploring the use of various governing instruments available to implement public policy in the health arena.

There are two products from this study of economic and political barriers to increasing prevention. The first is a summary of the evidence that can be found in the literature to support an understanding of healthy public policy in action. The second is a suggestion of potentially useful avenues of research.

THE LITERATURE: STRENGTHS AND WEAKNESSES

Epidemiology

The medical literature offers strong evidence of causal relationships between health risks and disease. The strength of these relationships is often disputed by the manufacturers or producers of a health risk, but we are now confident about the existence of many such links. For example, enough is known about the link between smoking and cardiovascular disease or cancer to justify the implementation of public policy aimed at reducing smoking.

However, further research into the causal links between risks and disease is needed. Public policy initiatives could be made more effective through the targeting of the more vulnerable groups. To this end, epidemiological research would also be valuable. The third important contribution of epidemiology would be to determine the effects of increased prevention and health promotion initiatives on health outcomes.

Barriers to a healthy environment

The recent literature also suggests that rather than victim-blaming, healthy public policy should focus on aspects of the environment that impact on health. Barriers to a healthy environment include:

- the belief that misery is part of the human condition;
- the difficulty of generating momentum for change;

- the jurisdictional disputes within government over control of a healthy environment; (Calnar, 1985)
- vested interests, for example, those who contribute to an unhealthy environment do not want change (Buck, 1985; Calnar, 1985; Smith, 1986)
- the uncertainty regarding the overlap between individual behaviour and social behaviour;
- the limits (in our form of democracy) to the power to legislate individual behaviour (Hill, 1978);
- the fact that we implicitly place different "economic values" on different lives or lifestyles.

The literature does not offer very much in terms of observations on the successful management of barriers to healthy public policy. This important aspect could be documented by those policy groups in government who have had either positive or negative results in their efforts to implement policy.

Research of a descriptive nature would be needed to augment our knowledge on how to circumvent barriers. The question to direct the research could be: "Given our knowledge of barriers to healthy public policy, what avenues have we found for the implementation of such policy, and are these avenues of general applicability?"

Social aspects

The body of literature that looks at individual life-style modification, disease prevention and health promotion from a more global perspective, draws some useful conclusions.

- Health promotion is justifiable on a social costs argument (your bad habits generate costs we all have to bear).
- Health promotion now focuses on "harm to self" rather than "harm to others".
- There are significant social factors in disease (e.g., poverty, unemployment).

The literature does not deal with policies that call forth policy responses from other government departments which may, themselves, contribute to health (i.e., second vs. first generation healthy public policies). Nor does the literature provide any reasonable set of criteria by which to identify a healthy public policy, or to evaluate the development of a new policy.

Of considerable importance to the research agenda is the development of criteria for healthy public policy. In addition, research is needed to study the mechanisms by which a first-generation policy might produce

a response (a second-generation policy) from another department.

Additional research is needed to develop measures that express the benefits of health promotion in relation to its social costs. The focus here should be more on effectiveness measures than on the "dollar" outcomes typical of cost/benefit studies.

Also, this research should include such indicators as: the number of people likely to benefit from a program, the size of the risk to which the population is exposed, and the effects of the risk. For example, some risks (e.g., the AIDS virus) have fatal outcomes, while others (e.g., butter) tend to cause fat deposition, which may contribute to atherosclerosis. In this case, the AIDS risk is more profound and immediate.

The Use of Governing Instruments

The public policy and political science literature has produced numerous examples of governing instruments in action. (Stanbury and Fulton, 1984) The Figure on the following page (also reproduced in the text of the full report) summarizes the use of these instruments in disease prevention and the identified barriers to their use. (The Annotated Bibliography also discusses this literature).

Our knowledge in this field could benefit from research describing the characteristics of different interest groups in Canada and their points of influence on the policy process. On the normative side, researchers should be encouraged to identify an appropriate role for interest groups when the objective is healthy public policy.

A Governing Instrument Approach

Governing instruments	Role in Prevention of disease	Economic and Political Constraints
Taxation	provinces want revenue, won't increase prevention efforts	political: can't tax consumer of health services
Tax expenditures and subsidies	negative effect on prevention, increases production	farmers and manufacturers are visible lobbying groups
Regulation	to limit advertising of products that cause diseases	violation of the Charter of Rights and Freedoms
Public ownership	public ownership of the health care system prevents responsible action to increase prevention; service "free" at point of delivery.	health insurance is, in theory, independent of risk
Suasion		
a) Mass suasion (education/promotion)	main strategy now in use	the disease focus is too late for many victims; people don't relate risk of disease to self
b) Pure political leadership	Epp with <i>Health for All</i>	charges of paternalism
c) Suasion with inducements	no smoking in the work place; request it, then impose it	powerful lobbies are not amenable to suasion
d) Monitoring and information disclosure	reports on changing rates of smoking	monitoring may be very costly
e) consultation leading to co-optation	prominent Liberals on boards of tobacco companies co-opt other policy makers	Liberal party will protect tobacco companies; some PCs do also
f) Planned release of confidential information (leaks)	to focus attention on newly identified risks, to target research and funding	reporting violation of regulations controversial

POLITICS

Much of the literature on political behaviour in Canada is anecdotal and derived from the news media. Several systematic and analytical articles and books have recently provided more structure to the literature. Information for the section on political constraints has been drawn from both sources.

Of significant interest is the proposition that territorial disputes and lack of coordination among government departments is a political constraint to achieving healthy public policy.

Research is needed to identify the causes of disputes and lack of coordination among government departments. Suitable incentives to alter this behaviour should be proposed.

ECONOMICS

This paper has focused on those constraints to health and health care that fall within standard definitions of economic behaviour -- production, distribution and consumption. It also extends to topics that include market failure in health care, economic incentives for health, lifestyle as a choice, and markets for disease prevention.

The literature suggests that healthy public policy tends to be thwarted by redistribution of wealth to producers of economic goods; that interest groups hold more power than the general population; and that costs and benefits of many economic activities are conferred on different groups.

INCREASING PREVENTION: POLITICAL CONSTRAINTS

CONSTRAINTS	CASES		
	Smoking	AIDS	Acid Rain
power of lobby groups	tobacco lobby	a gay issue or an epidemic?	large U.S. and Canadian users of fossil fuels
government uncertainty (confusion of interests)	excise revenues vs health	limited to the ministry of health (or employment, education and housing)?	provincial or federal regulation of polluters? International implications
lack of coordination among government departments	health vs agriculture subsidy to tobacco farmers	health vs assured housing or schooling for AIDS victims	Ontario Hydro vs environment department vs consumer education to use less electricity
"business links" between lobbies and politicians or senior bureaucrats	prominent federal Liberals on boards of tobacco companies	none apparent	Alice Arm, AMAX and Lieutenant Governor of Ontario
impotent regulation	easier for government to "educate" to limit consumption than to regulate production/sale	potential quarantine of AIDS victims by B.C. legislation	no enforcement of regulations or of emissions

Research on economic constraints on healthy public policy should be coordinated with work on governing instruments (*how* to control economic behaviour) and with research on factors that contribute to the economic power of interest groups in Canada. Of particular interest should be those industrial groups whose products or processes pose a health risk.

Several economic constraints to healthy public policy are summarized in the following table. The

purpose of the table is to identify similar factors at work in all three policy cases. The smoking case is an example of a behaviour or lifestyle risk; AIDS is an example of the risk associated with a communicable disease; and acid rain demonstrates an environmental risk to health. Thus, all three primary theories of disease are represented.

INCREASING PREVENTION: ECONOMIC CONSTRAINTS

CONSTRAINTS	CASES		
	Smoking	AIDS	Acid Rain
Divergence of costs and benefits	Is the early death of a smoker a cost or a benefit to society?	Health care confers no benefits, has cost to society.	Fossil-fuel users and ore smelters treat environment as a "free" input; public loss of wealth.
Power of industry	No government uncertainty, but large and vocal objection by industry.	Blood products industry now tests for AIDS antibody.	Powerful manufacturers threaten job-loss if emission-control standards are enforced.
Social costs occur with a time-lag (inter-temporal relationships)	Effects of smoking are cumulative. Side-stream smoke also deleterious to health.	Difficulty in targeting "cause". Is the loss of a minority group a social cost?	Loss of lakes and forests occurred slowly. Hard to target SO ₂ , NO ₂ culprit.
Traditional redistribution of wealth	Tobacco is most profitable consumer product ever.	Not applicable unless drug manufacturers benefit.	Distribution of wealth to polluters from the general population.
Some inputs essentially "free"	Smoking is a voluntary act (except for those addicted); the smoker is a "free" input.	Free transfer of AIDS removes use of civil law as a source of restitution.	Use of air and water as free inputs to manufacturing.
Government tax benefit	Excise revenue an incentive to promote smoking.	None, unless early death saves pension fund.	Government may bear clean up costs without production benefit.

THE CASES

The cases (policy areas) examined in the full report represent an example of each of the three major theories of identification of health risk. Smoking represents the *lifestyle theory*, AIDS is an example of a contagious disease or the *germ theory*, and the effects of acid rain are described as representative of the *environmental hypothesis*. No case is examined exhaustively. Examples of political and economic constraints given in the literature are cate-

gorized by theory, to indicate how one's perspective leads to a focus on a different subset of arguments. In addition, each theory leads to different strategies for promoting health.

It is not immediately evident that any further research efforts in this area would be fruitful. The benefit of this method of classification is simply to structure the problem so as to generate useful alternative strategies for problem-solving and policy direction.

SUMMARY OF CASES

	Lifestyle Theory	Germ Theory	Environmental Hypothesis
Example	Smoking	AIDS	Acid Rain
Diseases	heart disease chronic obstructive lung disease (COLD) cancer average age at death 62	respiratory distress pneumonia risk of death 100% average age at death 30	kills forests, fish and wildlife increases allergic distress increases incidence of COLD excess annual death rate 19.5 per 100,000
Prevention Strategies	health education smoke-free workplace taxes on tobacco	health education isolation screening	advocacy—bringing issue to public attention monitoring and enforcing regulations
Political Barriers	lack of evaluation of effectiveness of government action in the light of general social change "gentleman's agreements" between government and the tobacco companies prominent Liberals work for, or sit on the Boards of Tobacco companies	the minority groups currently at risk for AIDS are not a big enough constituency to merit attention high risk groups are not a major constituency	the community link between polluters and recipients of acid rain is lost; there is no political jurisdiction harm to the population as a whole is seen to be small, while benefits to specific industries are large
Economic Barriers	revenue from tobacco excise is a source of general revenue for federal and provincial governments	early identification of AIDS carriers may cause job loss, discrimination	polluters threaten major job loss if industry becomes less profitable through pollution control

POTENTIAL OF INFORMAL CAREGIVING TO THE ELDERLY*

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*** Summary version**

HIGHLIGHTS

- The proportion of elderly people in our society is higher than at any time in history. The government is faced with the challenge of working out a partnership between the formal and the informal caregiving networks, as a means of preventing the elderly from losing their independence. By extension, the government must also determine how available resources can most effectively be allocated between the networks in support of this objective.
 - Planners who wish to utilize the informal care network must evaluate its real potential for assistance. It is especially important to consider people's degree of willingness to assist older family members, the possibility that support may not be available from informal caregivers, and the limits of the informal care network.
 - For any partnership between the two networks to be effective, certain actions must first be taken. These include:
 - defining the role of each partner
 - identifying the populations at risk
 - decentralizing services
 - bringing community and institutional services into proper balance
 - reviewing the role played by professionals
 - ensuring that elderly people receive adequate incomes and that their requirements for special equipment are met
 - promoting workplace policies that support caregivers.
 - Research is required on parent abuse, the present contribution of the informal network, and the potential impact of the two networks on each other in a partnership situation.
 - Needs and resources should also be analyzed. Specifically, research is required in the following areas:
 - the social pressure on women to take on caregiving roles, often at the expense of their working lives
 - men's potential to be caregivers
 - relation between the givers and receivers of care
 - the capacity for care of the informal network
 - the effectiveness of home-care services
 - So that trends can be monitored, baseline data on the health of the elderly is needed, using such indicators as age, sex, income, health status, disabilities, etc. Comparative international data is also needed.
 - Although in the new partnership government's role should be that of catalyst and monitor and not necessarily the provider of all services, this does not release government from its responsibility to ensure that all Canadians have access to adequate social and medical services.
 - In the effort to prevent loss of independence among the elderly, intersectoral collaboration and coordination of services are two vital elements.
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INTRODUCTION

People aged 65 and over, commonly called "the elderly", today represent close to 10% of the Canadian population. This proportion will have increased to 13% by the turn of the century, and probably to over 20% by the year 2030.

A similar phenomenon is apparent in all industrialized countries. Already, some countries have the proportion of elderly people that Canada expects to have by the end of the century (e.g., France: 13.9%; Sweden: 16.4%; West Germany: 17%). This increase calls for major adjustments since this is the first time in human history that such large numbers of elderly people, representing such a high proportion of the population, have lived for so long.

The adjustments we have to make are all the more challenging because of the difficulty of predicting what kind of assistance the elderly are likely to need in the future. Some people believe that with improved lifestyles, increased incomes and medical advances, future generations of seniors will be healthier and require less care. However, others see no reason to believe that there will be any change in current trends. While it is true that life expectancy has increased, there has been no corresponding increase in the probability that these extra years will be spent in good health. Furthermore, medicine is powerless in the face of many chronic illnesses that afflict elderly people.

Against this background, the following questions arise: Will the state be able to increase, or even maintain, its current level of formal care and services? Will there be an even greater shift towards transferring those responsibilities now assumed by the formal social and medical networks to the family and friends of elderly people?

The key challenge confronting the government is that of preventing the elderly from losing their independence by working out a partnership that takes into consideration the potential of the informal network while reallocating resources accordingly.

In the following pages we will: a) present a summary of our review of the literature; b) identify gaps in knowledge, data required and research priorities; c) discuss major political and social considerations.

SUMMARY OF THE LITERATURE REVIEW

Beginning with the questions identified above, we found close to 150 articles from around the world examining the role of the family, the state and community organizations, the problems ex-

perienced by those receiving care, and possible service mechanisms.

The family is the main source of care for the elderly. Can it be expected to continue playing this role in the future, bearing in mind that it is increasingly being disrupted by profound changes such as divorce, single parenthood and shifting family structures? The family is also facing new types of challenges which undermine its capacity to assist its older members: geographic mobility, immigration, the fact that a greater number of 18- to 25-year-olds are remaining at home, the relatively limited amount of space in the home, the possibility that two or three generations of older family members may need assistance (because of increased longevity), and ever-increasing pressure on particular individuals because families are getting smaller.

If we consider the loss of independence as a continuum, it becomes clear that both the informal and the formal care networks have an important role to play in the prevention effort. This paper emphasizes the contribution that can be made by the person's family and friends in this area. Informal caregivers can assist in a variety of ways, by performing material tasks as well as by providing moral support. Their contribution is generally considered to be vital to the health and well-being of older people, not only because it helps to delay or prevent institutionalization, which itself creates problems of dependence, but also because it complements and completes the care and services provided by the formal network. The principal caregivers are family members: the spouse and children of the older person and, occasionally, brothers and sisters or other family members. Neighbours and friends may also help. Regardless of the circumstances, most informal caregivers are women.

A family that takes on responsibility for an older member experiences many stress-related difficulties, such as less free time, fewer social activities, role overload, family conflicts, disruption of the family's routine, fatigue, and deterioration of physical and mental health. The costs associated with caregiving are far from being minimal; indeed, the financial, social, physical and, in particular, psychological, costs may be very significant. The situation is especially difficult if the caregiver is the older person's sole source of assistance, or if the latter suffers from mental affliction.

The recipients of care are also faced with painful difficulties. Over-protection by the caregiving family may slow down the process of rehabilitation for the older person with a disability, making further inroads into his or her independence. Older family members may also be the victims of abuse. However, as in the case of caregivers, their main difficulties are psychological in nature. Elderly people are ambivalent about turning to the family for care. With their independence reduced, they find it difficult to accept that

they can do little in return. Problems may arise in the relationship between the parent receiving care and the child providing it. As the child's sense of commitment grows, that of the parent may wane. Moreover, there may be conflicts of opinion concerning the parent's state of health, or the parent may compare his or her situation unfavourably with that of the child. Although it may on the whole be less difficult to accept assistance from friends and neighbours, their potential to help is actually far more limited.

In Canada, as elsewhere, prevention is a major objective of the formal health care network. Various home-care programs have been designed and these are probably in the vanguard of efforts to promote independence among elderly people within a context that acknowledges the assistance of family and friends. However, implementing such programs is difficult from a budgetary standpoint, since it is the hospitals and long-term care institutions that currently receive most of the funds allocated to care and services for the elderly. Moreover, the members of the informal and community networks are not easily integrated into the formal network.

Planners with a genuine interest in utilizing the informal network must evaluate its real potential for assistance. Three things must be considered: the willingness of people to help older family members, the possibility that support may not be available from informal caregivers, and the limits of the informal network. All studies show that people are willing to help older members of the family. However, this willingness may be at odds not only with material and family obligations, but also with certain other values that are central to western society. Some individuals may receive little or no support from members of their personal network. As a result, they risk earlier institutionalization, a recognized factor in accelerating the loss of independence. Individuals who have no family and those who are very old are the most vulnerable in this regard. Compared to their counterparts of lower socio-economic status, people with higher incomes tend to have wider social networks and to be in a better position to meet the cost of having someone provide care. However, such individuals tend to receive less direct assistance from their children, who may live and work far away. The loss of a spouse may be more difficult for men than for women. It is important for planners to recognize that there are limits to the informal network, limits associated with the difficulties experienced by both the caregiver and the person receiving care, but, most importantly, with the physical and psychological state of the older person. Certain principles, linked to these limits, have been identified. They are: children cannot be viewed as an unconditional source of assistance to meet the needs of their parents, personal assistance can generate health care costs when infor-

mal caregivers burn out and, finally, there is a danger of a "boomerang" effect, that is, women who have recently entered the work force may resist becoming caregivers, a role that they are being required to take on more actively than ever.

Various proposals have been put forward for making optimal use of the resources of the informal network. The limits of this network must be acknowledged if a balance is to be struck between the informal network (especially the family) and the government. The formal network can provide, or promote the provision of, various means of support to caregivers. It may be assistance of a direct kind such as: day programs for older people, respite care, home help or meal services, financial incentives, ergonomic and other home equipment adapted to individual needs, long-distance electronic monitoring/communication devices (telephone relays). Complementary measures may also be considered: setting up information, training or support groups, raising awareness among the elderly about the role played by informal caregivers, reinforcing support already given to caregivers by family and friends, and providing professional help when specific difficulties arise. Perhaps the greatest challenge the formal network faces is planning a partnership which recognizes the complementarity of the two networks. Such a partnership, aimed at preventing loss of independence among the elderly, must take account of the needs and the well-being of the caregiver as well as those of the person receiving care, within the framework of government financial constraints. However, it seems unrealistic, at least in the short or medium run, to forecast that reductions in the services now provided by the formal network will lead to enormous savings, because such cutbacks will have to be offset by new forms of care and services to those in need of it, and the provision of support and information to caregivers. So far, little has been written about possible strategies for promoting an effective partnership. Some of the key elements of such strategies would be:

- defining the role of each potential partner;
- targeting accurately the "at-risk" populations;
- decentralizing services;
- bringing social and community services into a proper balance with medical services;
- revising the role of the helping professional from the perspective of both the person receiving care and the person's family and friends;

- guaranteeing sufficient income for the elderly in case of loss or lack of independence;
- facilitating access by the elderly to housing that is adapted to their needs;
- encouraging policies to support caregivers in the workplace.

GAPS IN KNOWLEDGE, DATA REQUIRED AND RESEARCH PRIORITIES

What conclusions can be drawn from this literature review? Considerable attention has been given to the difficulties experienced by all parties—caregivers, those who receive care, and planners. Nevertheless, further research must be undertaken to enable us to better understand the problems and predict future trends. In the following paragraphs, we discuss those issues that we believe should be accorded priority in future research.

Towards a More Detailed Description of the Difficulties

Parent Abuse:

In view of the seriousness of this problem, the World Health Organization (WHO) recommended in 1984 that a study of the prevalence, causes and consequences of the abuse of elderly parents by their children be undertaken as a matter of urgency. According to the Organization, front-line teams (doctors, nurses) play a vital role in the prevention of abuse. In preparing our review we found no articles that provided specific data on the problem of abuse within the informal care network. Data on this subject should be gathered from the various relevant groups in Canadian society.

Contributions of the Formal and the Informal Networks:

There are some indications that care provided by the informal network can prevent or delay a person's loss of independence. However, the actual amount of care provided by informal caregivers remains unknown. A research project integrating the contribution of both the formal and the informal networks could yield results that would be of considerable use in the planning of a partnership aimed at preventing the loss of independence among the elderly.

Interaction Between the Formal and the Informal Networks:

There has been little research on the interaction or the interdependency between the formal and the informal networks that provide care to the elderly.

The informal network is characterized by reciprocity and mutuality, qualities that it must retain. Therefore, as Walker (1987) suggests, the potential impact of the interaction between the two networks must be studied so that the nature of informal caregiving is not impaired by bureaucratic ways of thinking.

Walker (1987) raises the thorny problem of the tensions that currently exist between the formal and the informal networks; in this regard, professional as well as union reactions to the partnership concept merit closer examination.

Towards a Prospective Assessment of Needs and Resources

Although important, a description of the problems is useless if it is not accompanied by a prospective study of needs and resources available. In this regard, planners should pay particular attention to the following:

Women and Assistance—Development of the Caring Capacity:

In most cases, women are the main caregivers to the elderly. Women's progress in the labour market will probably have a significant effect on the future caring capacity of the informal network. A closer look at the following questions would make it easier to understand and predict how the informal network's capacity is likely to develop.

- Under what specific circumstances do men assist the elderly?
- What attitudes do men have regarding a possible commitment to an older parent?
- According to Pitrou (1986), women are constantly at risk of having to give up their careers. It is therefore important to understand the structural influence exerted by employment and income on informal support (Walker, 1987).
- How can women reconcile the various roles they have to play?

Relations Between the Givers and Receivers of Care:

The attitudes of older people towards their informal caregivers, as well as those of caregivers towards the person receiving care, must be studied more thoroughly. Particular areas for attention (according to Ehrlich, 1985) include the meaning of dependence and the question of mutuality and reciprocity in the life patterns of caregivers and people receiving care. This latter area will take on a special significance in the future for older people who are sufficiently well-off to be able to pay for private care.

Identifying the Thresholds of Informal Caregiving:

While the problems experienced by caregivers have been relatively well-documented, little is known about the conditions and circumstances (for example, the degree of support the caregiver receives from family and friends) that facilitate the task and help to make the experience a positive one (Noelker and Wallace, 1985).

It seems that older people are more often institutionalized because of disability than because of a lack of goodwill on the part of family and friends. Criteria should be established to determine the threshold beyond which home care becomes impracticable. Ideally, this threshold should be examined in the framework of pilot experiments where the formal network is already operating directly (if only partly) to assist both the elderly person and the personal network. It would be interesting to compare the levels and types of formal support provided to those who care for the elderly in the various provinces, as well as outside Canada, and to study their effect on the informal network.

In order to prevent the resources of the informal network from being depleted, it is important to know the exact conditions in which, without becoming unduly overburdened, the informal network can be effectively encouraged, strengthened or supported by the provision of formal aid (Walker, 1987).

The "New Seniors"—Evolution of Their Situation:

There has been an overall improvement in the financial situation of the elderly. However, significant disparities remain: some live on old age pensions only, while others, particularly the "new seniors" who belong to the middle class, enjoy comfortable incomes, which open up for them opportunities that were once inaccessible to anyone over 65.

Many older people are also in far better health than were their counterparts 15 or 20 years ago. It would be worthwhile to study in greater depth current differences among older people, according to a number of indicators (age, sex, income, health status, disabilities, etc.) and to use these baseline data to track future trends.

Effectiveness of Home-Care Services in Canada:

Given the limits of home-care services currently offered in Canada (these differ from one province, and one region, to another), how and to what extent do the programs in place prevent the loss of independence among the elderly?

Comparative International Data on Caregiving Systems:

There are too few articles that compare the approaches of different countries to similar problems while at the same time providing a clear picture of the prevailing socio-political context in the respective countries. One good example is an article by Curtis (1987), comparing home-help systems in France and England.

The establishment of international panels of experts (researchers and representatives from relevant government departments), or at least the dissemination of their conclusions or the results of their discussions, would certainly provide invaluable information to all those who are concerned about preventing the loss of independence among the elderly. In this respect, the WHO (1984) document for Europe is extremely useful.

POLITICAL AND SOCIAL CONSIDERATIONS

Planners who wish to develop social policies aimed at preventing loss of independence among the elderly need to take account of certain political and social considerations which are discussed below. They are linked to one of the following objectives:

- preventing loss of independence;
- developing a partnership based on the caring capacity of the informal network;
- reallocating resources accordingly.

Preventing the Loss of Independence

First, we must acknowledge that older persons' independence should be maintained by all means, regardless of its current degree, and regardless of whether they are institutionalized or not. The aim is to make life tolerable, if not pleasant, for the elderly, who should be encouraged to maintain all their other abilities in order to be as independent as possible. In general, preventive measures that are designed for the population at large are also appropriate for the elderly population: good eating habits, exercise, hygiene, and detection of disease and disability.

It is widely recognized (even though little evaluative research has been done on the subject) that the provision of home services can halt the loss of independence and may even reverse the process altogether. On the other hand, institutionalization, even when it is absolutely necessary, seems to be a precipitating factor in the loss of independence. This is because the environment serves to increase

the dependence of the elderly on those around them (see Roy, 1987). The deleterious effect of institutionalization in this regard is well illustrated in a study carried out by Lefebvre-Girouard (1986).

Preventing the elderly from losing their independence is relatively widely accepted as being a desirable objective. In its 1986 report submitted to Quebec's *Commission d'enquête sur les services de santé et les services sociaux* (Commission Rochon), the Association des Centres de services sociaux du Québec emphasizes the need to develop policies that consider elderly people as individuals who continue to live full lives, whose needs and abilities must be considered as a whole, and whose independence must be encouraged and respected. The fundamental objective should be to ensure that, irrespective of the physical, psychological or social condition of the older person, the intervention does not hinder the development of his or her potential.

There is, however, a noticeable gap between this philosophical approach and its application in practice. The clearest indicator of this is the obvious inadequacy of resources allocated to home-care services. Because of this gap, the public may become skeptical about the idea of developing a partnership, and view it as merely a money-saving exercise which fails to ensure the safety as well as the physical and mental well-being of the elderly.

Scientists and professionals in the formal network are agreed on the need to prevent the loss of independence. What is now required, however, is more action on the part of those who are in the best position to implement policies and programs consistent with this objective.

Development of a Partnership

Let us now examine the political and social factors to be considered if a partnership based on the caring capacity of the informal network is to be developed.

We have summarized here a set of proposals for using the resources of family and friends. The importance of recognizing the limits of the informal network, providing support to caregivers as well as those receiving care, and planning the partnership have also been discussed. But what would be the political and social significance of the state's taking a changed role in this area?

First, it should be noted that the "Zeitgeist" is probably ready for such a change. While some people speak of a swing of the pendulum, we prefer to call it a transition because the situation will never return to its former state. The literature reviewed highlights the fact that Canadians have grown used to a certain level of commitment on the part of their government, and that they would not be willing to go back to the past in this regard indeed, such a change would be utterly unthinkable,

given the evolution of the family and the challenges associated with aging in our society. Yet, the winds of change do appear to be blowing with regard to such fundamental issues as deinstitutionalization, non-institutionalization and privatization.

A frequently described scenario is one in which the state would not necessarily be the structure to "take charge", distribute services, and build and manage nursing homes. It would be the state's responsibility to offer all the services for the elderly. Rather, its role and functions would be to support the various parties in discharging their responsibilities and facilitate their task. It would be up to the state to ensure that the services were in place and accessible, as well as to establish standards of quality.

The state's role appears increasingly to be that of a catalyst and a monitor. As the director-general of a local community service centre (CLSC) recently observed, what is tragic for many older people is not that they cannot afford the services they need, but rather that they cannot find them (Roberge, 1987). Although community resources are burgeoning just at the right moment, when the government is in the process of redefining its own role, these resources should not be required to take on the specific responsibilities of the government. This view is shared by the Canadian Council for Social Development (1985), which maintains that community services are not a way of privatizing what has become, through social consensus, an appropriate role for the public sector in Canada. Moreover, although volunteer services and mutual aid are two elements of community services, this does not absolve the government from its responsibility to guarantee that, when the need arises, every Canadian has access to adequate and appropriate social and medical services (p. 8).

We have seen that the expansion of home-care services is important when it comes to preventing the loss of independence. However, home care is but one of the elements that must be implemented in working out a true partnership. In addition to providing support to caregivers and to people receiving care, the government will have to encourage partners, new ones included, to make a concrete or stronger commitment to preventing the loss of independence among the elderly. It has to be responsible for ensuring that retirement, income and housing policies are coordinated. A more stringent fiscal policy, for example, might induce people to plan their finances right through to their retirement years. The government will have to join forces with social, economic and cultural players, such as municipalities, organizations offering recreational services, school boards and community organizations, particularly those established by the elderly. From the literature review, it is clear that some difficulties

will be encountered. Will firms be interested in providing support to employees who are caring for elderly persons? Is this type of encouragement likely to hinder the progress of women in the labour market? Pitrou (1986) emphasizes the danger women face in this regard, and describes how some countries have dealt with similar situations. In the Soviet Union, for example, women are released from the work force at age 55 to staff collective child-care centres. This unveils a striking paradox: those same "babushkas" were previously suspected of transmitting pre-revolutionary principles and values to younger generations.

It goes without saying that the government, by establishing a partnership that draws on the capacity of the informal community network, is not thereby released from all responsibility in this area. Far from it. Rather than seeking to free itself from its commitment, the government needs to find new ways of becoming involved, while also identifying those sectors that will continue to be mainly under its authority. In meeting this challenge, such a change could contribute significantly to the integration of all available resources to achieve "Health for All," and perhaps *by* all.

Reallocation of Resources

Developing a partnership aimed at preventing the loss of independence among elderly people implies not only entering into dialogue with various parties outside the formal network, but also reallocating resources within that network. This calls for organizational, budgetary and ethical decisions that are in keeping with emerging ideology and values.

From the organizational point of view, the formal network must not only expand its geriatric services. The government must also have the

courage to properly define the mandate of the various institutions (chronic-care hospitals, nursing homes, CLSCs and the home-care services they provide, etc.) and their inter-relationships with one another, and to ensure that the users of services as well as the resources are divided appropriately among these institutions. The government must also promote collaboration and complementarity between the private and public sectors as well as with the community.

Funds currently allocated to home-care services are inadequate (in general, but certainly in Quebec). As the literature review revealed, it is difficult to develop a partnership between the formal network and various other parties in a context where the medical model dominates the strategies for intervention, and absorbs most of the funds available. Indeed, a very large portion of health care services is used by a very small percentage of elderly people (less than 5%) and these services are used mainly in the last year of life (see Roy, 1987).

There are also ethical issues to consider: are we prepared to spend more to ensure better physical and mental health for the elderly in the last years of life, and to accept a corresponding reduction in the funds allocated to extremely expensive measures that may prolong the life of our elderly parents by a few days or a few weeks? Disregarding the influence of the medical model, how can we decide how much should be allocated to preventing loss of independence among the elderly, and how much should be left to curative measures?

No one can afford to remain indifferent to these questions, for we are entering a new era in which the number of people aged 65 and over will continue to burgeon, while our financial and familial resources may already have reached their limit.

THE FAMILY AS A TARGET OF HEALTH PROMOTION INTERVENTION*

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* Summary version

HIGHLIGHTS

- The examination of the family (rather than the individual) as a target of disease prevention programs has been the subject of few well-designed studies.
 - Overall, descriptive data from studies that have addressed the relationship between health behaviour and
 - social support
 - health beliefs
 - parental health behaviours
 - family functions suggest that this is a field which merits further exploration.
 - Specifically recommended is a family-focused, longitudinal health promotion program administered by primary health professionals, which tests several interventions simultaneously. Subjects would be families at high risk of atherosclerotic cardiovascular disease, and intermediate as well as longer-term outcomes would be assessed.
 - Researchers carrying out such a study must ensure that
 - the families concerned both initiate their own involvement and participate actively in the intervention; and
 - steps are taken to minimize any negative effects arising from labelling families as being at "high risk".
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INTRODUCTION

Because many behaviours and elements of lifestyle are developed within the family and because genetic factors are important in predisposing to many chronic illnesses, it makes intuitive sense to direct some disease prevention activity to families as opposed to individuals. We set out to review available literature looking for evidence to support or refute the merits of such an approach. The perspective examined was that of primary care practice rather than public health. However, some studies examined did employ public health strategies. In general, few well-designed studies have been published that address this issue.

LITERATURE REVIEW

Medical as well as psychological literature was reviewed using computerized and manual search strategies. Studies addressing the relationship between health behaviour and the following categories were examined: 1) social support 2) health beliefs of oneself or one's family members 3) health behaviours of one's parents (modelling) 4) family functioning characteristics. Health behaviours examined included health promotion activities, early disease detection and compliance with treatment. The latter was included because treatment of many diseases such as hypertension can be seen as secondary or tertiary prevention.

Articles were evaluated using a scheme developed by Sackett and Haynes to evaluate compliance research. Two adaptations of the scheme were developed to evaluate the studies on health beliefs and modelling on the one hand and family functioning on the other. These schemes are included in the full report.

The literature on social support as a predictor of compliance in treatment and/or prevention was examined because much of the social support studied is that provided by family members. Twenty-six studies are described in the bibliography to the full report. In half of these the social support studied was in fact spousal. In 11 of the studies no relationship was found between social support and compliance. In terms of the strength of experimental design of these studies, Table 1 (see full report) indicates that more of the studies showing no effect utilized a more powerful design. However, six of these addressed the complex problem of obesity, whereas only three of the studies showing an effect of social support addressed this problem. Other clinical problems studied were: cardiovascular disease/hypertension (eight, four positive and four negative); smoking cessation (three, all positive); and chronic

pain, stroke rehabilitation, hemodialysis, arthritis and diabetes (one each).

Thus, the literature in this area gives a very mixed picture. Workers in this area have suggested that part of the confusion is due to the fact that social support is not a single variable. Differences in measurement instruments mean that "social support" is not the same entity in different studies. This fact may explain some of the differences in results reported. Moreover, available instruments may fail to measure those aspects of the size and nature of a person's social network that do have an impact on his health behaviour.

We now turn to family health beliefs as predictors of health behaviour. The literature consists of 11 descriptive studies and one controlled trial. The controlled trial found that administering threatening communications to mothers was associated with better weight loss in their obese children. Mothers' beliefs correlated with compliance with otitis media treatment in two studies. Children's health and illness behaviours were found to be correlated with beliefs in one study but no such correlation was obtained in three others. Health beliefs were found to predict the participation of families in one community-based cardiovascular risk-reduction program.

On the other hand, six publications report a relationship between family modelling of health behaviour and the practice of health behaviours by children or young adults. Five of these are descriptive studies. A quasi-experimental design was used to test the impact of parental attendance at the first session of a school dental health program on dental health. A positive effect was found.

Three studies report a correlation between the smoking habits of high school and college students and those of their parents. Health practices of adults correlated with those of their adolescent children in two reports.

This body of work suggests that parental behaviour is a much better predictor of child behaviour than are parental beliefs. Thus, saying "Do as I say, not as I do," is advice that is likely to be ignored.

The family system is not in fact one single kind of system with a uniform way of functioning. Families vary in their communication styles, in their degree of cohesion, in the degree to which roles are defined and in their decision-making styles. These differences are likely to affect family responses to preventive interventions on two levels. Some kinds of families may respond poorly (or well) to any activity directed to the family unit. In addition, certain intervention styles may work well with certain family types.

Seventeen studies have examined these issues in various ways. Conjugal style was examined in five,

parental style in three, and a wide variety of family characteristics in 10. Fifteen of these 18 were descriptive. Various conjugal styles, parental styles, family environments and socio-demographic characteristics were identified to be associated with compliance with therapeutic regimens or prevention activities. Most of this body of literature suffers from the use of non-validated measures of the family characteristics of interest. Moreover, none of these studies involve interventions. They attempt to identify the salient characteristics of patients and families who practise disease prevention and obtain good results in disease treatment.

Approaching husbands in order to get women to have Pap smears was more effective in couples with cooperative and merged roles. Adults in marriages where there was a high level of companionship between partners had better general health and used more preventive services. A partnership or autonomous marital style was associated with better adherence to a program for secondary prevention of cardiovascular disease. Parents who informed their children and gave them a lot of autonomy had children who engaged in more health promotion practices than parents who used a disciplinary approach. Drug and alcohol use by adolescents was less common in families where there was firm control than in those where tension levels were high and rejection was frequent. Health behaviour has been associated with family cohesiveness and promotion of autonomy as measured on the Moos Family Environment Scale.

FUTURE DIRECTIONS

The medical and social science literature that examines the family as a possible target for prevention programs is not extensive. As is appropriate for a domain in which little is known, most of the work to date is descriptive. This descriptive data is sufficient to encourage workers to develop and test manoeuvres directed to families.

Future work must address the methodological issues raised by Sackett and Haynes' scheme. The most powerful study design that is appropriate to the research question and is feasible should be used. Measures of independent and dependent variables should be valid and reliable. This holds for easily-defined variables such as blood pressure as much as for complex constructs such as family functioning.

Some workers have used measures of family functioning that have been tested extensively for validity and reliability and we examined these in terms of their utility in future research in this area. Several of these measures require a lengthy family interview and are thus not of practical use.

Two self-administered scales will be discussed here. The Moos Family Environment Scale (FES) was developed in 1981 by a group of social ecologists in California who have developed several social climate scales. FACES III (1985) is one of several measures of family functioning developed by a group of psychologists in Minnesota. The Moos group bases its work on theories of many kinds of social environments, whereas the group that produced FACES III bases its work on a theory of family functioning specifically. Both scales have undergone extensive development and testing (mostly in the United States) to reach their present forms, including much work in factor analysis and construct validity, and both perform well. The FES has three forms: Real, Ideal and Expectations, and these have been used extensively for marital and family counselling. Some studies have demonstrated a change in FES following family-oriented interventions for psychological/behavioural problems. FACES III has two forms: Perceived and Ideal. Because it was developed very recently it has not been used in as many studies as the FES. FACES III contains 20 items, whereas FES has 67. Both of these instruments are appropriate research tools in this area. Non-validated measures should not be used.

Outcomes should be measured, not evaluated using patient reports. Because many suggested interventions are designed to prevent problems many years in the future, intermediate outcomes must be assessed. For example, cardiovascular disease prevention programs should evaluate exercise, diet, smoking, blood lipids and blood pressure, because myocardial infarction and stroke would not be expected to begin to occur in the children of the families involved for at least 30 years.

SOCIAL CONSIDERATIONS

For family-focused interventions to prove fruitful such programs must be effective when administered by primary care health professionals. For most Canadians this professional is the family doctor. Most behaviour-change programs described have been carried out by psychologists with highly motivated patients. They are, therefore, not appropriate for population-wide application. Family physicians need a tool that they can learn to use quickly (i.e., requires skills they already possess) and that has proven efficacy in a general population. The fact that such a manoeuvre is addressed to several patients at once and uses family members rather than physicians to deliver reinforcement would make it appealing to busy family doctors. However, no such program can be recom-

mended until it has been carefully tested and proven efficacious.

The behavioural science literature abounds with evidence of success in changing health behaviours. However, maintenance of the new behaviours has not been achieved. Manoeuvres directed to families should include training individual family members to reinforce one another's desired behaviours.

Trials need to be conducted on the general population, not on volunteers. Families need to be consulted about what they want. Those of us in health care provision and policy should not be approaching families with powerful tools to change behaviours that they have no wish to change. The initiative should come from families.

Much well-intentioned work in early detection of risk factors serves to label individuals and families with a chronic incurable condition. Professional advice to those labelled usually involves major changes in their way of living. We must carefully examine physical, psychological, social, economic and legal effects of this process, and adapt programs to minimize negative effects. If programs do

not involve the "subjects" as active participants in their development we will be further medicalizing normal members of the population.

PRIORITY QUESTIONS FOR RESEARCH

The next step should be the development and testing of a family-focused health promotion program. The program needs to be developed by family physicians in consultation with behavioural scientists. Testing needs to be carried out in a primary care population, not with volunteers. Because families at high risk for atherosclerotic cardiovascular disease can be identified and are quite common, and because alterable risk factors are well known, such families are a logical target of such programs. Follow-up, even using intermediate outcomes, needs to be long, therefore it makes sense for more than one type of intervention to be devised and tested simultaneously by different groups of researchers.

PREVENTION OF INJURIES IN CANADIAN CHILDREN AGED 0-14 YEARS*

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*** Summary version**

HIGHLIGHTS

- In Canada, the number of child deaths resulting from injuries is higher than the combined number of deaths of children resulting from cancer, circulatory diseases, infectious diseases, congenital anomalies and diseases of the nervous and circulatory systems. Motor vehicle accidents is the leading cause of death among Canadian children, followed by drowning, burns, choking and falls.
 - Prevention programs that focus exclusively on voluntary behaviour change, even when properly designed and evaluated, are of limited effectiveness.
 - The most beneficial prevention programs are passive in nature, and focus on modifying the environment rather than behaviour. It appears, then, that the mechanism of the Health Promotion Framework which holds the most promise for reducing unintentional injuries to children is that of creating healthy environments.
 - Although much is known about how to prevent injuries in children, ensuring that the innovations are used is still a major challenge.
 - Ascribing fault in child injury situations must be recognized and avoided, in light of the fact that children are not as able as adults to judge the risks they may be taking.
 - Research is required in a number of areas related to child injury. Within the federal government, research efforts should be coordinated, perhaps by a special injury research unit. The impact of injury prevention measures on jurisdictions in which health is not necessarily a priority must also be carefully considered.
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INTRODUCTION

Injuries are the leading cause of childhood death throughout the industrialized world, and Canadian rates are among the highest for both boys and girls. Injuries result in more deaths of children than the combined number of deaths from cancer, circulatory diseases, infectious diseases, congenital anomalies and diseases of the nervous and respiratory systems. In 1930, deaths from disease among children ages 1-4 were eight times as common as injury deaths, but by 1980 the death rate from all diseases combined had decreased almost to the level of the injury rate, which had declined by only half. For children ages 5-14, the two death rates converged in the 1960s.

While the numbers of victims of injury in studies of mortality reflect the importance of the subject, the true enormity of the problem is captured by expressing these losses in potential years of life lost (PYLL) before the age of 65. The 837 Canadian children under the age of 15 dying of injuries in 1984 were denied 49,000 PYLL as a result of premature death.

Having determined the toll injuries extract annually, the "contribution" of the different agents responsible needs to be considered. The leading cause of death in Canadian children is the motor vehicle, followed by drowning, burns, choking, and falls. The ranking of fatalities by PYLL usually parallels that of the crude death rates. However, when the very young are the group primarily afflicted with a specific injury, and the death rates for similar injuries are comparable, shifts in disease prominence can occur. In 1984, drowning was superseded by burns as a cause of PYLL, for while there were 120 drownings representing 7063 PYLL, the 118 burn fatalities occurred among a young age group reflected in 7097 PYLL. The crude death rates reported are likely underestimates of the true magnitude of child abuse and suicide, and possibly homicide. Of epidemiological and social interest was the finding that handguns were implicated in only 1% of intentional childhood deaths in Canada, compared to over 50% of such events in American pediatric mortality reviews.

The "injury control" field has rapidly evolved since 1940. These developments are chronicled in Appendix II to the full report.

As part of the examination of previous injury preventive initiatives, the review will note if these efforts simply described the characteristics and scope of the program and/or the qualifications of its personnel (structure), whether the intervention actually determined the extent to which the target group accepted or adopted the suggested preventive measure (process), or if the endeavour measured the impact of the program on the burden

of illness associated with the selected injury problem (outcome). Moreover, the quality of the evaluations will be graded using the criteria developed by the Periodic Health Examination (PHE) Monograph Task Force. (The PHE criteria used in the methodological assessment and the limitations of this approach are presented in Appendix A to this report and in Appendix III to the full report.)

The agents and the corresponding preventive programs were selected for review on the basis of their contribution to crude death rates and PYLL.

Motor Vehicle Accidents

In the realm of unintentional injuries, the automobile poses the greatest risk of fatal injury to children. They die not only as occupants of automobiles, but also as a consequence of coming into collision with motor vehicles. The unique size and physical characteristics of children under the age of five years requires that they be transported in specially designed seating if injury is to be avoided. These same characteristics predispose them to more severe and different patterns of injury when struck as pedestrians. Moreover, 25% of all pediatric occupant trauma occurs in non-crash circumstances such as sudden stops or swerves. Technological active preventive measures have been readily available since the late 1960s. Infant and child carseats for younger children could reduce fatalities by up to 90% in both non-crash (primary prevention) and crash (secondary prevention) situations. Similarly, lap and shoulder seatbelt use by 5-14 year olds could reduce deaths by 50% - 60%. Despite the apparent effectiveness of infant and child restraints and seatbelts, parents use these devices less than 10% of the time. Educational programs on seatbelt use (category I type of research) have failed to improve voluntary compliance. Moreover, initiatives performed by health professionals have only assessed compliance with use and not whether this effort is associated with better outcomes (fewer injuries). Even these efforts, when carried out as randomized trials with direct observation of use (rather than reported utilization by respondent) resulted in only modest success. The results have prompted a call for a re-examination of this approach.

However, when these effective technologies are made a condition of operating a motor vehicle through government regulation, rates of use in the range of 50% - 90% can be achieved. The supporting studies could not be conducted as random trials, but were instead, careful comparisons between times or places

NOTE: This summary paper was originally referenced. Reference lists are not however being included with summary reports. All references are available with the full report or as a separate list. (See page 7 for information on how to obtain this list.)

with and without the intervention (category II-3 studies). In spite of enhanced compliance with legislation, fatalities did not fall in a proportionate fashion: usually only in the order of 10% - 20%. While inherent weaknesses of the study designs could explain this phenomenon, one other possibility is that up to 90% of infant and child carseats are not properly used. In addition, the small percentage of drivers not wearing seatbelts also happen to be the group of drivers more often involved in fatal mishaps, accounting for a smaller-than-expected reduction in mortality with increased use of restraints. Based on expert opinion and a limited number of descriptive studies of air bags (category III), it is suggested that this passive preventive measure could reduce front seat occupant mortality among older children by 50% - 70%.

Children as pedestrians pose a particular problem. Education programs on acquiring street-crossing skills have not been shown to affect outcomes, and in at least one instance actually increased the risk of a mishap. The most promising approach is to separate the child from the traffic, either through education programs for children to avoid the street (category II-3 studies, one "process," one "outcome," or through engineering or architectural changes (category III).

Drowning

Drowning is a major source of pediatric mortality. Unfortunately, teaching children to swim has not been demonstrated to be an effective means of combating the problem. In one report, only 30% of submersion victims were non-swimmers. However, reductions in drownings involving swimming pools can be achieved by an active preventive measure—the fencing of swimming pools—which is especially effective for the 0-4 year old age group (category II-3 study design). Fencing has reduced such drownings by up to 80%. This significant achievement was realized by strictly enforcing a local ordinance requiring such barriers. In an adjacent suburb where the voluntary approach applied, no such preventive gains were made. Prevention of drowning in other non-pool bodies of water, including the bath tub, remains the subject of ongoing parental counselling, a measure that can only be supported by expert opinion that it affects outcomes (category III evidence). One potentially useful active secondary preventive measure that still has not been evaluated but is widely advocated is the public's being able to promptly administer CPR to drowning victims (category III expert opinion).

Burns

In the field of burn prevention, the most sophisticated, well funded, and expertly designed program (category II-2) educating the public on preventing thermal injury was only able to show an improve-

ment in knowledge, and this did not translate into improved outcomes, for "neither the school program nor media campaign reduced burn incidence or severity." A burn prevention measure holding greater promise is the smoke detector. Not only are these safety devices being included in building codes, but a number of jurisdictions are requiring retrofitting of dwellings with these alarms. Moreover, studies (category I) show that when advised of the merits of smoke detectors, the public will purchase them. However, the impact of these efforts have yet to be assessed in comparisons of outcomes — frequency of fire deaths. Similarly, while tap water scalds can be reduced by decreasing hot water tank settings, and programs have succeeded in securing such efforts by the public, these measures have not been actually evaluated as to their impact on outcomes. A more productive approach might be to either lower settings of the hot water tank thermostats at the factory, or have the power company meter readers perform this task routinely as part of their duties (category III). A major passive preventive gain has been the passage of more stringent flammability standards for children's sleepwear. This legislation not only reduced the number of these injuries, but also decreased the severity of the burns (category II-2 research studies). A promising (category III) passive preventive measure will be the development of self-extinguishing cigarettes, since careless smoking accounts for 30% 50% of household fires.

Poisoning

Marked improvements in childhood poisoning frequencies have been occurring. While health information programs do increase knowledge (category II-3) most preventive programs of this nature have failed to demonstrate improvements in injury reduction. However, two passive preventive efforts, one primary and the other secondary, have had significant impacts on rates of poisoning. These measures are mandatory child-resistant closures, and the reduction in the number of baby aspirin tablets per bottle to a non-toxic dose (category II-3 studies). The role of regional poison control centres in initiating early intervention is another major accomplishment in poison prevention (category III).

Falls

Finally, an innovative active prevention program has shown that falls from apartment buildings can be diminished through a give-away program of safety guards coupled with legislation requiring their installation. A key element to the success to this preventive effort is attributed to the close monitoring of compliance with the regulations by public health personnel.

RECURRENT THEMES

In examining the various preventive programs developed for reducing deaths due to unintentional injuries, a few recurrent themes become evident. Programs that focus exclusively on achieving voluntary behaviour change, even when properly designed and evaluated, appear to be of limited effectiveness. In fact, the PHE Monograph recommends counselling on unintentional injuries, but emphasizes this suggestion cannot be justified on scientific grounds. An issue that needs to be considered is the frequency of activity required to secure the preventive benefit. The more often the effort is needed, the less likely the measure will be pursued. The other factor influencing success is the amount of effort required; the simpler the activity the greater the probability it will be performed.

As was illustrated in the different active prevention programs reviewed, a major enhancer of program participation was legislated incentives (penalties). However, these inducements will be effective only as long as there is adequate enforcement. It is generally agreed that the most beneficial programs have been ones that are passive in nature and where gains are made in modifying the environment rather than behaviour. The control of handgun sales (not available for sale) and corresponding number of fatalities attest to the success of this approach. Another advantage of passive measures is that they, unlike active programs, are usually not influenced by changes in personnel. Consequently, in the Health Promotion Framework, the health promotion mechanism with the most promise for reducing unintentional injuries is that of environment, despite being "the most complex and the most difficult".

If currently available mechanisms to reduce injuries were to be implemented nationally in Canada, 40% of pediatric injury deaths could be avoided annually (based on the assumptions used by Rivara in his analysis of available preventive measures).

The identification of acceptable and feasible technological solutions to a major health problem does not ensure that these innovations will be applied. Even if accepted, they may be associated with marked controversy. This paradox of possessing substantial knowledge on how to prevent injuries but being unable to fully utilize what we know warrants exploration.

OBSTACLES

The concerns and misconceptions of the population sustaining the injurious events must be addressed as well as those of their elected representatives. When talking about injuries, the word

"accident" is still widely used, as if unexpectedness or lack of intent were the primary feature of the injury process. The notion of "luck" or "act of God" has not yet been expunged. Even if the scientific approach to injuries gains acceptance, other obstacles to successful implementation of effective measures must be overcome.

The issue of ascribing fault, which has pervaded scientific as well as injury-control efforts, must be recognized and avoided. All components of the injury event must be given the same scrutiny and importance. The obsession with blame is at least partly the result of a legal system that focuses on allocation of compensation and punishment according to the intent or fault of the persons immediately involved. This attitude has pervasive effects on a wide range of activities in the realm of prevention—from data collection to an over-emphasis on the behavioural component of mishaps ("blaming the victim"). This approach is particularly inappropriate for children. Whereas adults may understand the risks they are taking, at least in general, children do not. In addition, children actually perceive themselves to be at low risk for injuries, lower than any other illness events in childhood. As well, for children and youth "the calculus for measuring the future benefits of today's sacrifice of investment in prevention is more difficult. For the young, the distance is greater, the benefits less certain, the imagination less experienced, the competing opportunities more compelling" (risk-takers dominate prime-time television), "and the burden of the present investments in prevention seemingly more costly relative to the limited resources available".

The area is further confounded by the different scientific agendas being pursued. Medical science research places great emphasis on finding and understanding the web of causes responsible for injury. By utilizing scarce resources in seeking academically interesting but relatively useless solutions to a problem, progress toward meaningful preventive efforts is inhibited. Traditional medical practice also enters the fray, despite its consumption of over 90% of health care expenditures, with a plea not to "abandon those who are already ill", a position that much of society may also share. Finally, and possibly most important, is the recognition that many of the preventive measures being entertained will have an impact on jurisdictions beyond health, and health is not necessarily a priority in these other sectors.

Child Abuse, Homicide and Suicide

The review also examined the evidence on preventing child abuse, homicide and suicide. This field is even less developed than unintentional in-

jury prevention, with most papers being of the category III variety or else focusing only on the treatment (tertiary prevention) of the problem. The remainder of the prevention programs focused on service provision rather than on outcome — prevention of abuse, assault and suicide. These systems have not been shown to significantly reduce the incidence or severity of child abuse or other forms of violence. The lack of basic research into prevention of intentional injuries has been recognized and solutions have been offered. In response, at least one category I trial on preventing abuse has been published.

Other Aspects of Injury Prevention

In the course of reviewing the epidemiological and methodological aspects of injury control and the milieu within which these measures take place, a number of key aspects were mentioned only tangentially. These facets include biomechanics, acute care and rehabilitation.

Injury biomechanics explores the mechanisms of physical and physiological responses to energy transfers in mishaps. An understanding of the mechanics of injury could lead to improvements through the design of less injurious environments. Moreover, while the limits of healthy young males to withstand rapid deceleration is known, refined data is not available on children nor are the effects of these forces on specific tissues appreciated for the pediatric population.

The speed and appropriateness of treatment (tertiary prevention/post-event) can profoundly influence outcome of an injury. The acute care process includes on-site decision making and management, and rapid transport of the patient to a hospital that can provide optimum care. The constituents of these trauma centres have been catalogued and can significantly enhance recovery (category II-3 and category III studies).

Once survival is assured, the focus shifts to the rehabilitation of the recipient of the damaging energy exchange. In the context of injury control, rehabilitation is the process by which biological, psychological, and social functions are restored or developed to permit an injured individual achieve maximal personal autonomy and an independent non-institutional lifestyle. As trauma units become more adept in the therapy of severe injuries,

demand for even more specialized rehabilitative services will increase. Studies supporting this element of injury control are of the II-3 or III categories.

SUPPORT FOR RESEARCH

A subject germane to injury control activities which also warrants more attention is support for injury-related research. While funding patterns in Canada were beyond the scope of this review, unless trends are drastically different from those of the United States, the federal expenditures on research in injury control is relatively small compared to allocations for cancer and heart disease. Moreover, decreases in injury rates would result from research requiring substantially less than is now expended on cancer and cardiovascular disease.

Furthermore, the management of injury research within the federal government needs to be coordinated, perhaps by the formation of a unit that would effectively administer a large-scale program in injury control. Divisions could be created that would be dedicated to the major challenges in this area - epidemiology, prevention, biomechanics, acute care and rehabilitation.

Specific recommendations in each of five research areas of injury control as well as funding and organization of this endeavour have been made in a series of publications on injuries. Detailed suggestions for each aspect of injury control have been gleaned from this work and are presented in Appendix IV.

Injury is the major health challenge in Canada. As has been demonstrated elsewhere, we have an opportunity to create a focused, coordinated research effort with the potential to save lives, reduce costs and long-term losses to the injured, their families and society. The unacceptable alternative is to let the loss of health and life to predictable, preventable or modifiable injuries continue unabated. Given the interest and will to address this problem expressed by the government, a national effort to tackle injury control is a necessary and logical extension of the Health Promotion Framework.

APPENDIX A — PERIODIC HEALTH EXAMINATION CRITERIA AND METHODOLOGICAL LIMITATIONS

The criteria utilized by the Periodic Health Examination include:

- I -Evidence obtained from at least one properly-randomized, controlled trial.
- II-1 Evidence obtained from well-designed, controlled trials without randomization.
- II-2 Evidence obtained by well-designed cohort or case-control analytic studies, preferably from more than one centre or research group.
- II-3 Evidence obtained from comparisons between times or places with or without the intervention. Dramatic results in uncontrolled experiments (such as the result of treatment with penicillin in the 1940s) could also be included in this category.
- III-1 Opinions of respected authorities based on clinical experience, descriptive studies, reports of expert committees.

It is important to recognize that not all preventive measures will be assessed by randomized clinical trials. In fact, this type of trial may not be the most appropriate methodology for many community-based interventions. In particular, trials involv-

ing known injurious risks cannot, for ethical reasons, be assigned "randomly" to healthy people for investigation. Moreover, randomized trials are not appropriate for studying long-term preventive effects since vastly longer surveillance times are needed. However, specific epidemiologic methodologies have been proposed for dealing with these community based, nontherapeutic interventions. As well, non-randomized comparison research can be performed rigorously. While the PHE criteria selected to evaluate preventive endeavours will be biased toward ratings of II or less, some programs lending themselves to random clinical trials have been assessed in this manner. When the method used for evaluation is a II but appropriate, then this will be duly noted. Within these limitations, the report will be able to utilize an accepted and valid means of assigning methodologic "quality" to preventive interventions.

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**ALCOHOL-RELATED PROBLEMS:
STATEMENT OF RESEARCH PRIORITIES
REGARDING THE PREVENTION OF
ALCOHOL-RELATED PROBLEMS USING PUBLIC
HEALTH APPROACHES**

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No highlights have been prepared for this paper. It is one of a set of papers commissioned separately from the literature reviews to suggest research priorities for prevention.

INTRODUCTION

This statement addresses main knowledge gaps in the area of alcohol-related problems from the perspective of furthering public health approaches to prevention. It addresses six areas of research priority that comprise three general thrusts. For each area, the general research question to be investigated is stated, as is the potential benefit to be derived from enabling program or policy development and implementation. An attempt has been made to relate these research priorities to the framework for health promotion contained in *Achieving Health for All* (1986). As well, in some instances, specific research issues within priority areas have been articulated as examples of research projects that might be undertaken.

IMPROVING THE KNOWLEDGE BASE

Research Priority One:

What are the full range and extent of alcohol-related problems experienced by the Canadian population and its various demographic and geographic segments, and what is the public health impact, in comprehensive terms, of these problems?

Research Priority Two:

Is it possible to specify, for both individuals and populations, patterns of alcohol consumption (apart from non-use) that are minimally hazardous to health, and that are associated with acceptable individual and public health risks?

These two research questions identify separate, but related, gaps in the fundamental scientific knowledge base that must be the essential underpinning of an effective health promotion/disease prevention initiative. The knowledge domain they encompass is the intelligence necessary to define the parameters of the health challenge of increasing prevention. It provides the rationale for the health promotion mechanisms (self-care, mutual aid, healthy environments) and implementation strategies (fostering public participation, strengthening community health services and coordinating healthy public policy) that address this health challenge. Thus, the potential benefit to be derived from augmenting our present knowledge base in these two areas is that such research will "enable" the entire Health Promotion Framework described in *Achieving Health for All*.

Under each of these general questions, a series of specific research objectives could be articulated. For example, regarding question one, a recent study in the United States¹ suggests that the mortality statistics usually used to define this aspect of

the public health impact of alcohol (as was the case, for example, in a recent Canadian report²) may be quite inadequate for this purpose, providing gross underestimates of the real toll. Further, available data are certainly inadequate to describe hospital³ and non-hospital morbidity, disability, lost productivity and other health and social costs, economic and otherwise, attributable to alcohol use. To address these gaps in knowledge, we need, among other things, better methodologies and more comprehensive and specific data sources. This will require specific research projects targeted to improving the knowledge base and to developing improved methods for measuring alcohol-related problems and their cost, in broad terms, to Canadian society.

An answer to the second question is clearly a fundamental prerequisite to increasing prevention in individuals and in populations. As information grows on the hazards of alcohol use, we find ourselves less secure in defining what is "safe". There may be no level of alcohol consumption that will always be risk-free for all individuals under all conditions. Nonetheless, we need, for both individuals and population groups, general and specific guidelines as to what constitute patterns of use, associated with minimal risks to health, that are acceptable. Some of the knowledge necessary to formulate such guidelines is already available, mainly from epidemiological studies, but it must be collated, assessed and synthesized. It must be explicitly augmented by new inquiries that address specific knowledge gaps in this area, and a mechanism for general and continual updating must be in place. This implies a specific research agenda involving the definition of terms, the quantification and evaluation of general and specific risks, and the development of general and specific guidelines concerning alcohol use. Current guidelines, as articulated, for example, at the national level in the United States by the National Cancer Institute,⁴ are far from adequate ("if you drink alcoholic beverages, do so in moderation").

CREATING HEALTHY ENVIRONMENTS

Research priorities three, four and five, relate mainly to the health promotion mechanism of creating healthy environments via the implementation strategies of coordinating healthy public policy and fostering public participation. Priority three deals with the area of the economic, physical and legal accessibility of alcohol and relates to the creation of healthier environments through the coordination of healthy public policy. Priority four concerns creating a healthier general environment by minimizing negative environmental lifestyle in-

fluences, while priority five concerns interventions in the drinking environment specifically. Both of these priorities have implications for public policy coordination and for fostering public participation.

Environmental measures have played a key role in the public health successes of past decades. The chlorination and fluoridation of water supplies and the pasteurization of milk are classic examples of the implementation of measures that resulted in major improvements in public health. In the alcohol field, there is a growing literature suggesting that environmental measures may be the most effective in increasing prevention,⁵ but further research needs to be done to strengthen and clarify the evidence.

Research Priority Three:

Is the control of accessibility to alcohol through economic, physical and legal measures effective in preventing alcohol problems, and, if so, how can public policy be coordinated to achieve this end?

Taken all together, the evidence is considerable that increasing the price of alcohol via taxation is a useful control measure, lowering overall consumption by decreasing economic accessibility generally, and, as a consequence, reducing alcohol-related mortality and morbidity. Further, studies of individual drinkers, including heavy drinkers, indicate that individual alcohol consumption is price-sensitive. Recent studies in the United States suggest a higher price sensitivity among young drinkers, with resulting beneficial effects.^{6,7,8} If confirmed, this would be a particularly important finding, with implications for decreasing the incidence (as well as the prevalence) of alcohol-related problems.

The role of tax exemptions in supporting the economic viability of alcohol in Canada requires thorough examination. For example, in the United States, taxpayers are permitted to deduct the cost of alcoholic beverages purchased for "ordinary and necessary business purposes." In 1979, these deductions represented a \$14 billion federal subsidy in support of alcohol consumption.^{9,10}

The evidence is mixed concerning the effect on overall and individual consumption of controlling physical accessibility (numbers of outlets, hours of sale, types and locations of outlets), and some aspects have not been adequately studied. Recent studies, including one in Ontario,^{11,12} do suggest that controls on physical accessibility affecting general populations are associated with reduced alcohol consumption and, in turn, with reduced alcohol-related mortality and morbidity. Some aspects of physical control may have effects that are problem-specific, and what affects one alcohol problem beneficially may have a contrary effect on another. This is a complex and multifaceted area that requires more research. The results of recent studies, however, are encouraging in indicating a role for

the control of physical accessibility in increasing prevention, suggesting that this should be a priority area for research.

With regard to the legal accessibility of alcohol, over the last few years growing information on the potential effectiveness of this measure has come from the United States, as individual states have implemented legislation to increase the legal drinking age. Now, as the result of a federal initiative, virtually all states have increased the legal drinking age to 21 years and much more information on the effectiveness of this nation-wide intervention can be expected. The primary goal of this measure is to reduce drinking-related motor vehicle mishaps in young persons. However, its potential impact goes well beyond the drinking and driving problem. Williams and Lillis¹³ showed that an increase in the legal drinking age in New York State from 18 to 19 years was associated with significant decreases in all drinking levels among 17- and 18-year-olds. Such changes in consumption could result in decreases in other alcohol-related problems, such as non-vehicular accidents, vandalism, delinquent behaviours and crime, and school problems. A recent study in the United States indicated that a clear majority of both parents of teenagers and other adults supported a minimum alcohol purchase age of 21, whether or not they resided in a state which already had this restriction.¹⁴ Whether this legal measure would be acceptable and effective in Canada remains to be determined. In Ontario, there is some evidence that the change in the drinking age from 18 to 19 in 1975 has been associated with a long-term differentially beneficial effect in young drivers.¹⁵

The potential benefit to be derived from research in this area is a strengthening of the knowledge base underpinning efforts to create healthy environments. Potentially, this health promotion mechanism could be affected by putting economic, physical or legal barriers between alcohol and all drinkers, thereby lowering overall consumption, and with it, alcohol-related health problems. It could be implemented through the coordination of public policy.

Research Priority Four:

How and to what extent does the marketing of alcohol, directly by the alcohol beverage industry, and indirectly by other means, contribute to alcohol-problems; how should potentially negative environmental lifestyle influences related to marketing be curtailed in the community in keeping with the creation of a healthier environment?

Measures to restrict alcohol promotion and marketing would be consistent with the comprehensive promotion of healthy lifestyles by ensuring a supportive environment. Whereas the alcohol beverage industry vigorously argues that its market-

ing efforts are intended only to affect brand preferences, a consideration of actual practices suggests that advertising and marketing strategies are designed to increase overall consumption by promoting the diffusion of drinking practices, recruiting new drinkers, increasing, or at least, maintaining consumption among established drinkers, and favourably altering perceptions of the role of alcohol in society, particularly among youth and other expandable markets. These marketing efforts can be viewed as negative environmental lifestyle influences that undermine the creation of healthier environments.

To date, research findings concerning the effect of advertising *per se* on alcohol consumption have been equivocal. However, advertising is only one part of the total marketing strategy employed by the alcohol beverage industry, an approach that places alcohol in its various forms in competition with all other beverages, including tea, coffee, fruit juices and soft drinks. The effects of this total marketing strategy on alcohol consumption and, by extension, on alcohol-related problems, have not been adequately studied.

A pervasive form of alcohol promotion occurs indirectly through the portrayal of alcohol use in the mass media. Investigators in the United States have documented the increasing portrayal of alcohol use and alcohol-related acts on television, noting that this portrayal is a significant distortion of real life.¹⁶ Wallack,¹⁷ in a study of prime-time television in the fall of 1984, estimated that a regular viewer would likely see more than 20 drinking acts per evening. Many of these acts portray alcohol in a glamorous context, and imply that its use is routine and even necessary, and that drinking is part of everyday life. The effects of these portrayals on the actual consumption of viewers is not clear. However, there is some evidence that the attitudes of children to alcohol may be adversely influenced. More research is needed. As well, it may be possible to test interventions aimed at educating media personnel with the objective of informing their decisions about the portrayal of alcohol use in the media.

The potential benefit of research in this area is that it will provide a knowledge base that enables program and policy initiatives aimed at creating healthy environments to be implemented. The control of the negative environmental lifestyle influences inherent in the direct marketing of alcohol by the industry could be effected by changes in public policy. Control of the negative environmental lifestyle influences inherent in the indirect marketing of alcohol, for example, those associated with the media portrayal of alcohol, might hinge more on the fostering of public participation, that is, on ensuring that the public or

specific groups therein, understand the impact of the message portrayed on the health of their communities, and that they seek and respond to opportunities to assert control over these influences.

Research Priority Five:

Are there interventions in specific drinking environments that are effective in preventing alcohol-related problems?

An innovative approach to increasing prevention that is targeted to specific drinking environments, known as "server intervention", has been proposed. Server intervention refers to a broad set of approaches for creating healthier social, physical and legal drinking environments in order to reduce both the risk of intoxication and the risk that intoxicated persons will harm themselves and others. It comprises three components, namely, server training, the legal context, and the drinking situation. Within these components are a network of elements focusing on servers (commercial and social), managers and owners of commercial alcohol outlets, criminal statutes, dram shop liability, alcoholic beverage statutes and regulations, alternative transportation (public and private), the interior and exterior design of drinking settings, and outlet location.

A multidisciplinary research agenda for the specific strategies has been outlined.^{18,19} Several aspects are being tested experimentally and early results are encouraging.²⁰

The potential benefit of this approach would hinge on both fostering public participation and on coordinating healthy public policy. While this innovation is targeted primarily at the problem of drinking and driving, such a comprehensive approach could have considerable structural and symbolic importance in reshaping regulatory functions and public attitudes toward the prevention of alcohol problems.

PROMOTION OF LESS HAZARDOUS DRINKING

The sixth priority relates to the promotion of less hazardous drinking and concerns primarily the implementation strategies of coordinating healthy public policy and strengthening community health services.

Research Priority Six:

Is it possible through specific public policy and community health service initiatives to facilitate the replacement of hazardous patterns of alcohol use with patterns that are less hazardous to health?

While there is evidence that public education programs do affect knowledge and attitudes, at

least to some extent, and may be useful in bringing about an understanding of and support for alcohol control measures conducive to healthier environments, it has not been demonstrated convincingly that such programs have resulted in behavioural change leading to a reduction in per capita consumption. Rootman,²¹ in a recent interview, concluded like many before him that the evidence for the effectiveness of these programs in controlling alcohol consumption and preventing alcohol-related problems is equivocal. He and others, however, have stressed the limitations of the data underlying this conclusion. Nonetheless, it appears that the new approaches should be sought to the promotion of less hazardous drinking, in place of more harmful practices.

Whether or not less hazardous drinking patterns would result from a general lowering of the alcohol content of beverages or actually limiting the physical availability of alcohol, is not known,²² but this approach seems feasible²³ and should be studied. While it seems likely that this would result in an overall lowering of alcohol consumption, it is possible that drinkers might adjust their consumption upwards to compensate for the decreased beverage alcohol content.²² It seems unlikely, however, that most drinkers would do so, particularly if the usual packaging and service units for off- and on-premise purchase remained unchanged. In one experimental situation, it was found that light beer was not readily discriminated from regular beer.²⁴ An alternative approach would be to decrease the size of traditional packaging and service units, while leaving alcohol content unchanged.

Further, the preferential consumption of lower-alcohol beverages might be facilitated by a price structure via taxation that favoured these beverages. In introducing preferential pricing, however, the cost of regular beverages should be increased relative to low-alcohol content beverages, for which prevailing prices should be maintained.²⁵ It would also seem important to maintain a price structure that would clearly favour the consumption of non-alcoholic beverages. In this regard, it should be noted that in parts of the United States, beer can be obtained at equal or less cost than soft drinks.²⁶

Changes in public policy to facilitate the preferential consumption of lower-alcohol-content beverages would be in keeping with changing public attitudes and consumption trends. In parts of the United States²⁷ and Canada,¹⁵ it appears that public attitudes are now less tolerant of heavy drinking, and that beverages preferences are shifting to low alcohol content beverages such as light beer, low alcohol wine, and spirit "coolers". The forces behind these changes in public attitudes and consumption trends should be explored, in light of

growing knowledge concerning the diffusion patterns of social behaviours. How can the diffusion of less hazardous drinking practices be accelerated?

Finally, there is now considerable evidence that it is possible in clinical settings to identify hazardous patterns of drinking in individuals early and to intervene effectively, replacing hazardous drinking patterns with less hazardous ones.²⁸ Skinner and colleagues^{29,30,31} at the Addiction Research Foundation (ARF) in Toronto have been at the forefront of research into effective methods of early detection in clinical settings, using simple measures that preclude the necessity for invasive measures which provide delayed information. Sanchez-Craig and colleagues, also at ARF, are at the forefront of studies into effective intervention in early hazardous drinking.^{32,33,34}

This work suggests that it may be possible to increase prevention in other non-clinical community settings, such as the workplace, by strengthening community health services through the incorporation of appropriate measures to detect hazardous drinking early, and offering counselling services regarding less hazardous drinking. This approach to promoting less hazardous drinking deserves study.

The potential benefit to be derived from research into the facilitation of less hazardous drinking patterns is that effective public policy and community service approaches may be identified. Given the general lack of impact to date of public education efforts, it seems important to explore these alternatives.

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MAIN GAPS IN KNOWLEDGE IN THE AREA OF PREVENTING MENTAL ILL-HEALTH AMONG ELDERLY PERSONS: KEY PRIORITY AREAS

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No highlights have been prepared for this paper. It is one of a set of papers commissioned separately from the literature reviews, to suggest research priorities for prevention.

**KEY AREA NO. 1:
DESIRE AND EXPECTANCY FOR
CONTROL AND SELF-MANAGEMENT
AMONG ELDERLY ADULTS:
IMPLICATIONS FOR HEALTH CARE**

Background and Rationale

Recommendations that elderly persons be given increasing control over their health and health care have become common in current literature. Although there is evidence that increasing younger individuals' control increases their sense of well-being (Rodin and Langer, 1977) and decreases negative responses to caregivers (Mills and Krantz, 1979), there is also evidence that the effects of increased control are not always positive for older adults who do not desire or expect control. Nevertheless, increased control (i.e., ability to regulate one's behaviour or environment) has also led to certain positive results, including better health among the chronically-ill aged, or those in institutional settings, and a decrease in mortality.

Given that older adults tend to be more dependent on health care than younger adults (Davis, 1976), and potentially more dependent overall, it is important to understand their health-care stresses in terms of control—what do they desire? what do they expect? In matters of health, how much control do they feel capable or desirous of exercising?

A number of studies in the United States (Folkman, 1984; Mills and Krantz, 1979; Smith et al., 1984; Thompson, 1981) have shown that among older adults, perceived control and individual differences with respect to control are important mediators of responses to stress and health care. Langer (1983) has suggested that, in general, the lower the perceived control over personal welfare and the health care system, the higher the level of stress response. Studying the relationship between age and expectancy for control, Lachman (1986) and Wallston and Wallston (1982) found that compared to younger adults, older adults hold significantly greater belief in the ability of "powerful others" (e.g., caregivers, physicians, adult children) to control their health. Haug (1979) found persons 60 years of age and over afraid to challenge the authority of their physicians. Thus, the older the patients are, the more likely they are to assume the non-participatory patient role (Cassileth et al., 1980) and to fear the consequences of exercising their own judgement.

Questions That Need To Be Addressed in the Research

Is the decreased orientation toward control of health and health care that is found among older

adults attributable to the fact that they hold different views from younger adults?

Research studies need to address such differences in the perceptions of elderly adults in relation to (a) *themselves* for example, why do older adults expect less control? do they perceive themselves to be more forgetful or cognitively incompetent about understanding health matters?; (b) *other persons* for example, are they fearful about questioning the decisions of physicians and other professionals lest they be rejected or denied access to the health care system?; and (c) *their interaction with their environment* for example, do they perceive caregivers and health care professionals as expecting older adults to play a non-participatory or passive role, and as considering it appropriate that they should do so?

Overall, it is suggested that greater perceived control may be associated with more positive attitudinal profiles and reduced stress responses in the elderly. In Canada, Reid and Zeigler (1981) have suggested that aging people who experience greater feelings of control over health outcomes are more satisfied with their lives.

Apart from the health care implications of desire and expectancy for control in elderly adults, there are major gaps in knowledge concerning: the relationship between chronological age and expectancy for control over health outcomes; the desire for control on a general level; and the desire for control on a health-specific level. Research is needed to examine elderly adults' control in their daily functioning, and their preferences with respect to the handling of personal affairs, self-care, health-related information, and control in specific health care situations (Smith et al., 1985).

Towards this end, studies are needed to assess the older adults' sense of (a) *self-efficacy with respect to desire for control in health*; (b) *self-efficacy with respect to desire for health-related information*; and (c) *general self-efficacy*, with respect to self-confidence in managing life-events, or lack of confidence leading to avoidance or withdrawal.

In summary, cross-sectional and longitudinal studies are necessary to:

- (a) determine the extent to which older persons, compared to younger adults, desire control, both in general and specifically in relation to health and health care;
- (b) examine the relationships between the following: age and people's health care beliefs and expectancies for control of *health outcomes*; those expectancies and the desire for control;
- (c) explore whether the relationship between age and expectancy for control remains constant across personal, social and health-environmental situations; and

- (d) plan intervention programs to assess the effects of choice, enhanced personal control and responsibility on the mental health of elderly people in both custodial and controlled community settings.

Potential Benefits

Results of the kinds of studies suggested above may help to shed light on whether the lowered desire for control exhibited by elderly adults is a product of ingrained fear and anxiety related to those in powerful positions. It must be remembered that most Canadian elderly adults grew up in an era when the omnipotence of professionals was less likely to be challenged. Thus, today's older adults may have more difficulty in questioning or asserting themselves within the health care system. If the research reveals subsets of elderly persons who genuinely believe that powerful others are better able to control health outcomes, then at least we will know that blind trust rather than fear and anxiety accounts for their diminished desire for information about health maintenance and control.

Surveys of elderly persons' beliefs, desires and expectancies for control may help to explain whether lower desire for control is associated with a faulty socialization process regarding health care professionals, or with repeated experiences with a health care system that encourages little personal control or expectancy for self-care and control. Should the socialization process be at fault, the next step would be to examine how this process might be changed with respect to aging individuals. As public health professionals, we must ensure that older persons feel there are sufficient information and consultation facilities available to enable them to make decisions about adhering to prescribed regimens of mental and physical health. The need to develop intervention programs which stress health care consumerism is becoming very important for those subsets of the aged population who depend heavily on the health care system. Such programs should emphasize the necessity for elderly persons to seek second opinions, and to ask more questions concerning the appropriateness of medical and mental health regimens prescribed by health care practitioners.

Before appropriate strategies/interventions for making the health care process more congruent with the needs of older adults can be developed, public health professionals must seek from the elderly persons themselves (both outpatients and inpatients) information regarding the factors which have led to a lowered desire for active participation in the health care process. The proposed research is also expected to identify environmental factors in the home, in community settings and in institutional settings which can promote in the

elderly an increased desire and expectancy for greater control, both in general and over health outcomes.

The general thrust of the research would be to identify, from a preventive mental health perspective, the developmental factors associated with personal control throughout the life course.

KEY AREA NO. 2: ASSESSING SERVICE AWARENESS AMONG ELDERLY ADULTS

Background and Rationale

Lack of awareness of public services among elderly persons has been cited in the gerontological literature as a primary reason for the under- or non-utilization of such services (Anderson and Newman, 1973; Coward and McCuan, 1985; Fowler, 1970). However, the findings on levels and correlates of awareness about community services are not consistent. The role played by community size or community ecological characteristics in awareness of public services among elderly adults is not as straightforward as is generally believed, and it requires considerable further study in Canadian urban and rural communities. Relatively few studies in Canada have examined whether awareness levels differ for rural and urban elderly populations, and fewer still have examined the relationship between awareness levels and community size (Ecosometrics, Inc., 1981).

Questions That Need To Be Addressed in the Research

Several factors suggest that there may be differential levels of service awareness among rural and urban elderly residents and among various subsets of the elderly population.

Three kinds of factors are presumed to account for the variation in service utilization by elderly persons. They are: *predisposing factors*, *enabling factors* and *need factors*.

1. Age, sex, race, ethnic grouping, material status, education, home ownership status and degree of contact with children are generally used as indicators of the *predisposing factors*.
2. *Enabling factors* facilitate or inhibit the use of services, and might affect awareness of services. Annual household income, car ownership status and availability of transportation facilities may be a few indicators of this factor.
3. *The need factor* indicates levels of problems, and it is presumed that those individuals with greater needs (e.g., handicapped, chronically ill, living alone) are more likely to seek or receive information. Summed scores of health dependency and activities of daily living also need to be entered into analysis as measures of need.

A central question that requires investigation is how community size, the urban or rural nature of the community and the predisposing, enabling and need factors operate, both directly and indirectly, to affect levels of service awareness among subsets of elderly adults.

Data are needed from various geographical regions, both urban and rural, concerning older persons' awareness of such essential community services as elderly visitors, home health, home help, home meals, hot luncheon sites, day centres and day hospitals, information/referral, legal aid and transportation, personal counselling, and crisis intervention services.

Further information is required regarding the services that are more frequently used, and the factors that impede the use of certain useful and needed services.

The sample should be derived from both males and females, rural and urban communities, white and non-white populations, residents and immigrants, and should include individuals who are married, unmarried, living alone and living with another individual. A wide range of household income levels and years of residence in the community need to be represented.

Experimental intervention programs need to be designed from a preventive mental health perspective, allowing groups of aging individuals opportunities for visitation to service sites, or for visitation at home by providers of community services. The impact of such intervention programs on the awareness of older community members needs to be assessed objectively.

Potential Benefits

Through multiple regression analysis, the strongest predictors of service awareness could be identified. Ecological characteristics (size, density, location of the population) that affect service awareness and utilization would also be identified.

The proposed investigations would identify services preferred but not available, and types of services available but not accessible. In particular, there is the need to identify factors mediating the accessibility and utility of some services (e.g., information/referral) which might have significant impact on the awareness of some services but not others. In addition, the investigation of community services could be expected to underscore the importance of looking at variations in the service awareness of various groups of elderly with respect to differing degrees of predisposing, disabling and critical needs.

If health and human services are to be delivered equitably to the elderly in rural and urban communities, public policy determining the distribution of health care services and the quality of services must be based on an accurate assessment

of the service awareness and service utilization of different subsets of elderly adults.

KEY AREA NO. 3: ADJUSTMENT TO RETIREMENT: PREDICTIVE AND MEDIATING FACTORS

Background and Rationale

Many theoretical and practical questions concerning the impact of retirement on the psychological well-being of older adults need to be addressed by research. As of June, 1982, there were 3.2 million Canadians over the age of 60 and 2.3 million over the age of 65. Statistics Canada projects that by the year 2000 the over-60 age group will swell to 4.5 million and that those over the age of 65 will number 3.4 million. This means that by the turn of the century, 12% of the population will be 65 years of age or older and entering into the first phase of retirement.

Thus far, investigations in both Canada and the United States (Cameron and Persinger, 1983; Lepine, 1982; Sakinofsky, 1976 a, b) have indicated that life-style changes such as those accompanying retirement are followed by increases in both susceptibility to disease and mortality. Studies of Canadian retirees (Lepine, 1982) have concluded that involuntary retirement is an important determining factor in suicide among the aged. Major role changes resulting from retirement often lead to boredom and a sense of purposelessness, resulting in an increased vulnerability to psychosomatic illnesses and depression. For some individuals, retirement can be a major life stressor which leads to negative psychological and physical consequences. However, there are also clear data suggesting that for a considerable number of elderly adults, retirement is positive in terms of both mental health and enjoyment of living. Many subsets of the Canadian elderly population adapt very successfully to the psychological transitions associated with retirement. What are the factors which account for the differences between those groups of elderly people whose adjustment is characterized by psychological well-being and satisfaction with life, and those who respond with depressive reactions and psychological disorders?

Questions That Need To Be Addressed in the Research

Studies in the area of retirement should have the major objective of identifying those variables which predict the difference between successful and unsuccessful adaptation to the various sub-stages of retirement. Atchley's dynamic theory views retirement as a process involving a series of substages, each with its own characteristic transitions, coping sequences and adjustments; and each integrated into the individual's earlier life ex-

periences and functioning skills. Atchley suggests that retirees' adjustments and adaptations need to be monitored in terms of affect changes, stress levels, role changes and role losses, through all phases: the remote phase of pre-retirement, the near phase of pre-retirement, the "honeymoon" phase of retirement, the reorientation phase, the stability phase, and the termination phase of post-retirement (Atchley, 1980; 1984).

The major thrust of future research studies must be to observe longitudinally those positive and negative cognitions, positive-negative affects, coping skills, problem-solving resources and stress-related experiences which distinguish subsets of elderly adults who adapt to the changes of retirement showing little or no pathology, from those who respond with pathological reactions. The subsets studied should be controlled with respect to financial status and health status.

Gaps in our current knowledge about the impact of retirement can only be filled effectively by planning studies that are longitudinal in design but based upon the available cross-sectional data. Especially recommended is the use of multidimensional scales that assess longitudinally the general well-being of cohorts of retirees, and provide fine-grained analysis of changes in health concerns, positive and negative affect, and cognitive behavioural changes respectively (e.g., changes in desire and expectancies for life control, loss of control, or goal-seeking cognitive and social behaviours, loss of life purpose, existential vacuum or purposelessness, cognitive-intellectual resources and behavioural coping skills, boredom, depression, loss of role, life satisfaction reduction, and stressful life experiences of retirees).

Potential Benefits

Longitudinal studies designed to observe subjects go through the several stages of retirement will provide information, knowledge and insight about the beliefs, orientations, skills and resources of subsets of elderly adults whose adaptation to retirement is characterized by increased life satisfaction and positive cognitions, affects and goal-seeking behaviours. The data thus obtained from multidimensional scales might help to clarify the relationship of several aspects of subjective and objective well-being of subjects (during their transitions from pre-retirement to terminal stages of post-retirement) to (a) the retirees' health status, (b) their past stressful life experiences, (c) earlier levels of cognitive-behavioural functioning, (d) current social supports and coping resources, (e) problem-solving and decision-making skills, and (f) control orientations.

Obtaining these kinds of longitudinal data via path analytic statistical procedure will also help to

identify predictive and mediating variables, as well as prospective and retrospective factors associated with healthy and successful retirement adaptations (as distinguished from unhealthy and pathological adaptations). The identification of potentially problematic areas relating to psychosocial adjustments and adaptations in retirement will help to suggest preventive cognitive and behavioural intervention programs for pre-retirees, and assist with the development of public policy concerning voluntary and involuntary retirement of the aging population in Canada.

KEY AREA NO. 4: ELDERLY ADULTS' PERCEPTIONS, ATTITUDES, AND EXPECTANCIES WITH REGARD TO COUNSELLORS AND THE COUNSELLING PROCESSES

Background and Rationale

The rapid increase in the number of elderly adults in the general population across Canada and the recurrent psychological needs attendant upon this growth are well documented in the gerontological literature. For example, the literature shows clearly that the present generation of elderly individuals has not been socialized into becoming "psychologically-minded" (Kahn, 1975; Zarit, 1980; Lasoski, 1986). The same literature on aging confirms that social policy-makers and service-delivery planners for older adults have been only marginally concerned with tapping and understanding the dynamics of their attitudes, expectancies and preferences with regard to counselling, and with identifying factors which may prevent them from seeking help. This reluctance on the part of elderly adults to seek the formal help of counsellors and guidance workers brings into focus the need to examine their attitudes, anxieties, expectancies and preferences with respect to help-givers and counsellors. Information about and insight into elderly adults' preconceptions, misperceptions and expectancies of counsellors may help to explain the current under-utilization of counselling assistance and services. Also, an in-depth knowledge of elderly people's reservations, anxieties, preferences, and expectancies concerning the counselling process may hold a key to better serving this population.

Previous research (Radloff and Teri, 1986; Raskin, 1979; Zarit, 1980) substantiates the point that the expectancies of in-patient and clinical samples concerning their counsellors and help-givers are clearly more selective and different from those of community-based elders, who have many more reservations, apprehensions and misperceptions. The attitudes, stigmas and barriers to inter-

vention and counselling therefore need to be identified more urgently among community residents and community-based elders, who may be reluctant participants in the health care system.

Questions That Need To Be Addressed in the Research

Towards this end, studies should be designed to assist in the identification of key attributes and characteristics rated by the elderly as being important for counsellors working with older adults, as well as the types of helping orientations and counselling styles preferred by elderly persons.

Neglected aspects of research in this area include an understanding of the elderly adults' preferences for the gender, age, power-base, counselling style and credentials of the help-givers.

For example, it is not clear whether older adults prefer to be matched with their counsellors in terms of age (equal age, older or younger), gender (same sex, opposite sex), race and ethnic background, power-base (highly-trained professionals, volunteers, peer counsellors) and level of intimacy desired in the relationship (mild, moderate or intense). Similarly, little is known concerning the personal characteristics and attributes sought by older adults in their counsellors, and the desired features of the counselling outcomes. In general, it is argued that service-delivery planners need to know much more about the views of the elderly with regard to counsellors and help-givers. For example, we need to know whether the elderly prefer a counselling style that is non-directive and non-confrontational, or, conversely, a style that is directive, leading, and full of advice-giving (Ford and Shor-done, 1980). There is documented evidence to suggest that one of the important factors in the under-utilization of counselling services by older adults is their fear of being mismatched with help-givers in terms of communication styles, power-base, gender and age preferences (Fry, 1986; Lasoski, 1986; Quadagno, 1982).

"Which factors of personal attitudes, expectancies and preferences are operative and how they manifest themselves are areas which need thorough and imminent examination" (Lasoski, 1986; p. 2).

Simultaneously lacking in the geriatric counselling area is the availability of standardized and validated psychometric scales to assess the anxieties, depressions, attitudes, expectancies and preferences of the elderly towards seeking professional help or counselling. Therefore, the development, construction and validation of appropriate psychological tests and instruments to appraise the psychosocial expectations, attitudes and preferences of the elderly should be an intrinsic part of the investigations. The psychometric scales that are cur-

rently being used with elders were validated on younger populations, and they use clinical diagnostic DMS-III criteria which are not necessarily valid for community-based adults.

Potential Benefits

Knowledge of the expectancies, misconceptions and preferences of older community members will contribute constructively to the geriatric practitioner's knowledge and awareness of the psychological orientations of the older adult. Data-based awareness, obtained from the studies proposed, would facilitate the help-giver's task of organizing and synthesizing their help-giving and counselling role around the perspectives of the elderly. At the same time, the development of much-needed instrumentation and psychometric measures validated on subsets of elderly populations would facilitate future research on the elderly. Along with other studies concerned with assessing psychological awareness of the older adults, the studies proposed would help to inform the development of social policies and programs aimed at improving the utilization of professional counselling services by elderly people.

KEY AREA NO. 5: PSYCHOLOGICAL AND SOCIAL CORRELATES OF DEPRESSION AMONG OLDER COMMUNITY ELDERLS: IDENTIFYING THE PREDICTIVE AND MEDIATING VARIABLES

Background and Rationale

The importance of gerontological research among community elders with mental health concerns such as depression, stress and anxiety has been grossly minimized, compared to the attention that similar affective disorders have received in other populations. Among those over 65 years of age living in community settings, the incidence of severe depression is expected to increase to 18 to 25% of the total population by the year 2020. Unless mental health practitioners and researchers serving the elderly are able to identify predictive and mediating factors in depression in the later years, the mental health of our senior citizenry may become worse instead of better. To support such an argument, one need only adduce data on alcoholism, suicide, social isolation and widespread feelings of hopelessness among the elderly (Blazer, 1982; Fry, 1986 a, b, c).

The most glaring impediment to the understanding and treatment of geriatric depression is the current absence of longitudinal studies designed to assess the precise nature of the interac-

tive relationship between physical health factors, psychosocial stress phenomena, and environmental systems. Looked at from an age-specific perspective, the clinical picture of depression, although similar for elderly and younger persons, may be quite different in terms of causes, and thus different in terms of the goals of diagnosis, assessment and intervention. A given clinical picture of an aged person may result from several unrelated but interactive causes, some of which reflect past and present psychosocial and biological stresses, and others which are age-specific and related to the stage of life (Fry, 1986 a). Assessment of depression in the elderly must therefore be conceptualized from an age-specific perspective that takes into account the elderly's unique health status, intrapersonal and interpersonal frailties, cultural sensitivities, and interpersonal situational reactions to social and economic losses, cognitive skills and deficits and temporary confusional states (Thomae, 1981; Schaie, 1981 a, b).

Until recently, studies of depression among the elderly have focused on single or unitary variables. Increasingly, it is recommended that future research into depression among elderly adults be undertaken within an interactive framework, and conceptualized from a developmental perspective which examines the impact of several social-psychological-cognitive and biological subsystems on the mental health maintenance of aging persons.

Questions That Need To Be Addressed in the Research

What is recommended, therefore, is longitudinal research designed to investigate the biological, psychological and social variables that predict the onset of depression during the later adult years. Within this longitudinal framework, the predictive variables in depression must be assumed to be mediated through both intrinsic and extrinsic factors. Social subsystems (such as perceptions of the health system, perceptions of social role and social support networks, social and emotional losses, socio-economic status, personality variables), daily functioning variables (such as mobility and activity levels) and perceptions of adequacy in health care must all be presumed to predict the emergence of depression in the late adulthood years.

In the predictive model, therefore, it is necessary also to isolate those social-psychological and environmental variables which are antecedents to or consequents of helplessness and despair in the later years, and which subsequently lead to irreversible depressive states.

Within the longitudinal studies proposed, community-based adults must be followed prospectively over a number of years. Initial assessment sessions must be designed to collect in-depth data on those early

risk factors which are indicative of a depressive state. Intermediate follow-up sessions are intended to collect data on those specific factors which are related to relative recovery or non-recovery from depression. This phase will provide data with respect to cognitive symptoms of depression, functional health factors, motivational and affective concomitants, social support networks, social role losses, etc. associated with recovery/non-recovery from depression by the elderly.

The specific research questions which need to be addressed in the longitudinal studies are:

1. What are the specific life-events, attributions and experiences of community elders which interact with their personality characteristics, attitudes and sense of self-efficacy to predict either successful adaptation or depression?
2. What demographic characteristics of the elderly and specific social support components, activity levels and factors of mobility interact with their life experiences to predict successful adaptation or depression?
3. Can a causal and predictive model of depression be developed and validated by identifying a series of antecedent-consequent relationships in the social support networks, demographic variables, life-event variables, cognitive control variables and health status variables of elderly adults? These relationships, if present, must be traced over a period of at least five years in order to be properly validated and assessed.

Path analytic methodological procedures are now in place which make it possible to study the interactions of multiple variables and to identify factors of three types: those which contribute directly to the development of depression, those which are predictive, and those which are mediating factors in the development of depression in older adults. While previous studies of depression have focused on selective clinical samples of in-patient elderly persons, it is recommended that there should in the future be longitudinal observations of community-based elders.

Potential Benefits

The proposed social-systems model of depression, if supported by the data, will have practical relevance to social policy administrators and service-delivery planners who are concerned with implementing service programs for the care of the elderly and for the prevention of depression.

Data on predictive and mediating variables in depression would be useful in designing community preventive action programs for elderly persons, or remedial intervention programs for those subsets of the elderly who are at special risk of depression.

Data derived from the validation of a social-systems model of depression may provide mental health

professionals with a basis for developing social-educational anticipatory and preventive health programs that would contribute to the future psychological well-being and adjustment of older adults.

KEY AREA NO. 6: REVISITATION AND RE-EXAMINATION OF THE PSYCHOLOGICAL WELL-BEING STATUS OF OLDER CANADIANS

Background and Rationale

The extraordinary attention paid by gerontologists to the topic of life satisfaction and well-being (e.g., George, 1981; Liang, 1985; Nydegger, 1977) probably originates in the popular belief that old age is a gradual, downward trajectory with ever-increasing levels of inadequacy, impairment, and physical and psychological decline. This has produced widespread myths and misconceptions about the status of older individuals with respect to their psychological well-being and their quality of life. Although literature reviews generally conclude that well-being does not decline with age, it must be recognized that many of these reviews date back to the 1970s and reflect cohort differences. There is reason to believe that new data emerging from the present group of older Canadian cohorts may present an entirely different profile.

Up to this point, most surveys of the psychological well-being of older citizens have been based on the assumption that such well-being is a direct reflection of objective circumstances, for example, objective health, family health, economic security, and independence in living and decision-making. Psychological well-being as a critical factor in the adjustment and adaptation of senior citizens remains of great interest in the 1980s. However, since the whole conceptualization and implementation of the concept of psychological well-being is a product of the 1950s, revisitation and re-examination of the concept in terms of the *subjective* experience of aging in the 1990s and beyond is critical to the elderly's mental health.

From an objective perspective, it is widely believed that poor health takes its toll on well-being, health worries increase markedly and old people are often assumed to be unable to cope or adjust to health threats and physical limitations. These objective indicators suggest an overall decline in the psychological well-being of individuals as they age.

From a subjective viewpoint, however, we lack knowledge of and insight into the personal and internal perspectives of older adults in the 1990s and the changes or stability in global well-being as perceived by the present cohort of elders.

For example, meaninglessness, lack of purpose in life, and lack of any desire to find meaning and purpose have been recognized by gerontologists as constituting a modern malaise that, if left unresolved, can lead to symptoms of anxiety, depression and ill-health (Ruffin, 1984; Levine and Croog, 1984). Few studies in recent years have attempted to get at the personal appraisals that older citizens make of their own psychological well-being and its relationship to their physical health.

Overall, therefore, the entire issue of the effect of meaningfulness on coping behaviours, adjustment processes and health outcomes remains uncharted territory, awaiting exploration by gerontologists (Reker, Peacock and Wong, 1987). Badly needed, therefore, are investigations that will address both the objective and subjective well-being of older Canadians, with particular emphasis on the subjective.

Questions That Need To Be Addressed in the Research

- How are different life events and experiences perceived and evaluated by older adults?
- Is old age as bleak a period as younger people commonly assume? Compared to younger adults, how do older adults rate in terms of (1) *Life Purpose* (zest for life, fulfillment, contentment, satisfaction); (2) *Existential Vacuum* (lack of purpose, lack of goals, free-floating anxiety); (3) *Life Control* (freedom to make life choices, exercise of responsibility); (4) *Death Acceptance* (lack of fear or anxiety about death); (5) *Will to Find Meaning* (striving to find meaning); (6) *Goal Seeking* (desire to achieve goals and to be on the move); and (7) *Future Meaning* (acceptance of future potentialities).

The objective of re-examining the above-noted questions would be to investigate age and sex differences in the processes of self-reflection and re-evaluation. As far as possible, future efforts to structure counselling approaches and counselling orientations for the elderly should be based upon the insight that is derived from studying the relationship between meaning and purpose of life and the elderly individuals' perceptions of well-being (Reker and Peacock, 1981).

- What changes, if any, are seen in the affective lives of older adults?
- Is it possible that death acceptance decreases in elderly individuals who have enhanced feelings of well-being, i.e., that in late life, high death acceptance is associated with low psychological

well-being, and individuals with high life purpose are most anxious about giving that life up?

- Is there a blunting of both negative and positive feelings in the later years? Is it possible that older individuals maintain their overall level of well-being because the frequency and intensity of both positive and negative emotions declines with age? This hypothesis of emotional blunting with age has been advanced by several authors (e.g., Malatesta, 1981; Schultz, 1985) but has seldom been tested with present cohorts of older Canadians.

It is essential that there be a multidimensional approach to the measurement of meaning and purpose in late life. Prospective panel studies and path analytic methodologies are needed to address these issues of mental and physical well-being in the later years.

POTENTIAL BELIEFS

The central questions of psychological well-being addressed in the gerontological research are inextricably linked with social policy governing the planning of mental health intervention programs for older Canadians. If, as it is widely expected they will, the prospective data show that subjective well-being neither improves nor declines with age, or that individuals adapt quickly to whatever circumstances they find themselves in, psychotherapy and counselling for older adults will likely focus on teaching coping strategies and adaptive mechanisms. If, on the other hand, the results rebut the existing negative stereotypes of aging, psychotherapy and mental health, interventions may have to focus on promoting existential meaning and purpose for old age. Preliminary findings attest to the importance of considering various life attitudes of older people when promoting health and welfare programs.

CANCER PREVENTION PRIORITIES FOR RESEARCH

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No highlights have been prepared for this paper. It is one of a set of papers commissioned separately from the literature reviews to suggest research priorities for prevention.

INTRODUCTION

Until comparatively recently, cancer was generally believed to be an inevitable concomitant of aging, despite the discoveries of external causes of cancer by clinicians such as Ramazzini, Pott and Rehn. During the present century, opinion has gradually changed, following the experimental production of cancer in animals, and later in tissue culture; descriptive studies of geographic variation in cancer incidence and mortality; and the demonstration in analytical epidemiological studies of strong associations between the risk of cancer and exposure to a variety of physical, chemical and biological agents.

During the 1950s and 1960s, the results of these experimental and epidemiological studies culminated in a new paradigm for carcinogenesis, that of a somatic mutation in a single cell, probably as the result of repeated insults to the genome, one of which could be inherited. Over the past two decades the brilliant studies of the molecular biologists have consolidated this paradigm, and are beginning to pinpoint the precise nature of the changes in the genome, and the mechanisms by which control of cellular growth is lost during carcinogenesis.

So far, this new understanding of the nature of carcinogenesis and the potential for preventing many types of cancer has not led to any definitive cancer prevention programs. Some of the reasons for this are discussed below. The publication by the Minister of National Health and Welfare of the document *Achieving Health for All*, with its identification of "increasing prevention" as one of the three main health challenges, provides a focus for the development of a coherent approach to cancer prevention in Canada.

The purpose of this paper is to identify the priorities for the research needed to develop such a program. Before doing so, it is necessary to clarify what is meant by prevention in this context and the kind of prevention programs around which the research priorities will be developed.

PREVENTION IN THE CONTEXT OF CANCER CONTROL

Figure 1 illustrates the modern paradigm of cancer development and progression and indicates the levels at which a comprehensive cancer control program could operate. The malignant process begins as a result of exposure of the cells of a susceptible host to carcinogens. The process is latent at first, the length of the asymptomatic period depending on the doubling time of the malignant cells, the vigour of the host response and the anatomical site of the tumour. Eventually

clinical symptoms develop, and, in the absence of treatment, progression to disability and death is inevitable.

This progression can be averted by interventions at three main levels, denoted on the diagram by I, II and III. These correspond roughly with the terms "primary prevention", "secondary prevention" and "treatment and rehabilitation" often found in the public health literature, but these terms are rather imprecise. Level I interventions are those which aim at avoiding or stifling carcinogenesis at its onset. This can be done in two ways—reducing exposure to carcinogens, or reducing the susceptibility of the individual to carcinogens. Level II interventions focus on the asymptomatic stage of cancer progression. Some tumours can be detected in this stage by special examinations. Alternatively, the individual's awareness of the significance of changes can be sharpened so that treatment can be started before the disease has spread. Interventions at this level presuppose the existence of effective treatment. Level III interventions include the various modalities of curative treatment. Improvements at this level come from better methods of abating tumour cells or controlling their growth, thus increasing the chances of survival, and from devices and supportive measures to reduce the disability of survivors. Not included on this diagram are the palliative care programs which are required to help the 50% of cancer patients who succumb to the disease. Important as they are, such interventions do not fall under the heading of cancer control.

Of the six broad strategies mentioned:

- I a) reduce exposure to carcinogens;
b) reduce susceptibility to carcinogens;
- II a) find asymptomatic cases;
b) increase awareness of early symptoms;
- III a) increase survival following treatment;
b) reduce disability of survivors;

the first four can reasonably be included under the heading of "prevention". This is a somewhat broader definition than that used in the document *Achieving Health for All*, where the emphasis is on the first of the six strategies "prevention involves identifying the factors which cause a condition and then reducing or eliminating them" but that document also emphasizes self-care as a health promotion mechanism, and, as we shall see, the first four interventions all involve individual participation as an essential element.

THE RESPONSIBILITY FOR CANCER PREVENTION

If cancer prevention programs are lacking, who is to blame? The answer is probably everyone and no

one. There are many possible roles and players. Health is constitutionally a provincial responsibility, but the federal government has a clearly demarcated role in some areas, such as taxation and regulation, which are highly relevant to cancer prevention. The federal minister has also a general responsibility for the stimulation and coordination of programs aimed at improving the health status of Canadians. The Health Promotion Framework lists three implementation strategies fostering public participation, strengthening community health services, and coordinating healthy public policy.

In all but one of the provinces, publicly-funded agencies have been created to deal with cancer—cancer control agencies, cancer treatment foundations, etc. These agencies were formed primarily to provide special treatment and diagnostic services, but several have an implicit, and some an explicit, responsibility for cancer prevention. The Cancer Control Agency of British Columbia has been a world leader in the development of early detection programs, and, along with the Alberta Cancer Board and the Ontario Cancer Treatment and Research Foundation, is moving towards more comprehensive programs of prevention. Such agencies are, however, clinic-based, and will need to move into the community to achieve their new goals.

Also governmentally supported, primarily at the provincial level but with varying degrees of local autonomy, are the public health units. Although heterogeneous in structure, these units all have legislated responsibilities in the area of disease prevention and health promotion. Faced with contagious disease, the public health authorities took, and continue to take, a disease-specific approach. However, in response to the challenge of non-contagious diseases they have tended to focus on risk factors, rather than specific diseases, as targets. This raises an important basic question of strategy which has not, perhaps, been fully addressed in this specific context. There are underlying currents of ideology and role definition which would make consensus difficult to achieve. The general approach outlined in *Achieving Health for All*, and in particular the strategy of "coordinating healthy public policy", would appear to favour an eclectic view.

Among the non-governmental agencies, the Canadian Cancer Society is most directly concerned with the cancer problem, although many associations of health professionals and other lobby groups are active in areas related to cancer prevention. The Canadian Cancer Society has a long-standing commitment to public education, and, more recently, has made major contributions to the National Breast Screening Study. The Society also supports the National Cancer Institute, the

committee structure of which includes consideration of research priorities.

DELINEATION OF RESEARCH PRIORITIES

If we accept that cancer will be a specific focus for prevention programs, the latter being community-based with inputs from several agencies, how can research priorities be shaped to assist in the development and implementation of such programs? Each of the four main prevention strategies described above involves the following process of elaboration:

- establishment of targets (risk factors for exposure, sites for early detection, etc.);
- quantification of importance (e.g., in terms of mortality);
- determination of potential for modification;
- choice of intervention strategy;
- evaluation of effectiveness of interventions;
- optimization of efficiency of intervention.

Within each strategy, the degree to which the process has already been elaborated varies, and the corresponding priorities for research also vary. In the analysis which follows, we review what is established and what remains to be established for each component of cancer prevention.

REDUCING EXPOSURE TO CARCINOGENS

The agents which are known, or strongly believed, to cause cancer in humans are listed in Tables 1 to 3 under the broad headings of physical, chemical and biological carcinogens. Those for which there is still some doubt or controversy are indicated by a question mark. For each carcinogen, the common methods of exposure and the main cancer sites are also given.

The carcinogenicity of ionizing radiation in its various forms, and of ultraviolet radiation, is well established. For these agents, the research priority lies to some extent in quantification (how much cancer is currently caused by ionizing radiation, especially at low doses? how much of the recent increase in melanotic and non-melanotic skin cancer is attributable to ultraviolet radiation?). Heat and physical trauma have long been incriminated as carcinogens, but the evidence is largely anecdotal. The possible role of trauma in relation to osteosarcoma and carcinoma of the testis is worthy of further exploration in the Canadian context. Whether elec-

tro-magnetic radiation is really carcinogenic is a clear priority for research at the present time.

The list of known chemical carcinogens is a lengthy one, but not perhaps as long as some would suppose. The status of alcohol still needs further clarification, as does that of lipids in relation to cancer of the breast and colon. The studies incriminating pesticides are conflicting and need duplication in the context of Canadian agricultural practice. Although the carcinogenicity of tobacco smoke is well established, we need to know more about the relative importance of the various components, particularly in relation to passive smoking. For most of the chemical carcinogens, though, we need to be able to quantify their importance in current circumstances. For example, how much do occupational or dietary exposure to chemical carcinogens contribute to the present cancer burden?

The list of possible biological carcinogens is expanding rapidly. Most of the Mendelian genetic syndromes associated with cancer are rare. Familial polyposis coli is an exception. Human papilloma virus has displaced herpes virus type 2 recently as the most likely candidate in the etiology of cancer of the cervix. More research is needed to establish the importance of endogenous hormones and endogenous metabolites as carcinogens.

Another perspective on our knowledge, and the gaps in our knowledge, of human carcinogenesis is provided by Table 4. The cancer sites are grouped under four headings: contact epithelia (exposed directly to the external environment), excretory epithelia (exposed to carcinogens excreted from the body), secretory epithelia (exposed to hormonal stimuli and perhaps to carcinogens carried in the secretions) and the non-epithelial sites (exposed only to penetrating radiation and chemicals passing the relevant barriers. For each group the contribution to cancer incidence and death is indicated, along with a qualitative assessment of current knowledge regarding etiology.

As might be anticipated, more is known about the carcinogens affecting contact epithelia and excretory epithelia than about secretory epithelia or non-epithelial tissues. The implications for future etiological research are clear.

There have been several attempts to summarize and quantify the current knowledge concerning the etiology of cancer. Most are framed on the basis of "risk factors" rather than specific carcinogens. The most celebrated synthesis is that of Doll and Peto (see Table 5) who based their estimates on cancer deaths. If cancer incidence were the criterion, then "geophysical factors" would loom larger, particularly in Canada, since most skin cancers and some lip cancers are due to exposure to sunlight. The precision of the estimates varies considerably. The estimate for tobacco is reasonably certain, but

those for diet, alcohol, infection and occupation are less precise. As already mentioned, these very uncertainties identify research priorities. Nevertheless, this list goes a long way to providing target exposures for preventive programs, and it is not necessary to wait for such research to be completed before proceeding further.

The next question to address is the extent to which it is feasible to modify exposure. In some cases, such as genetic background and reproductive history, modification is next to impossible. Like age and gender, these factors serve merely as risk markers for other interventions, such as early detection. Some types of exposure (e.g., occupational exposure to chemicals and medical exposure to radiation) can be changed primarily by regulation or by influencing selected target groups such as doctors. At the community level, however, the target exposures fall in the area of "lifestyle" use of tobacco and alcohol, diet, exposure to sunlight, promiscuity. A key research question in this context is whether modification of such behaviour is best accomplished by broadly-based health education programs or by individual counselling. Another issue is the importance of the milieu in which such programs are mounted, in particular whether community action programs can catalyze change in the behaviour of individuals. These questions have been explored, but not fully answered, by the intervention programs aimed at cardiovascular disease.

REDUCING SUSCEPTIBILITY TO CARCINOGENS

The possibility of reducing an individual's susceptibility to carcinogens has been mooted for a long time, but it is only recently that any practical intervention has become feasible. Three approaches have been suggested—artificial stimulation of immune mechanisms, use of retinoids, and use of anti-estrogens.

It has been clearly established that immune mechanisms play an important role in the individual's response to the presence of a malignant tumour, and immunotherapy is used clinically under certain circumstances, although often with disappointing results. There is also a good deal of evidence that immune mechanisms influence an individual's susceptibility to carcinogens. In particular, patients with suppressed immunity, due to drugs or other illness, are more likely to develop some forms of cancer such as lymphoma. A few years ago there were suggestions that BCG might be used to prevent lung cancer in subjects at particularly high risk, e.g., those exposed to both asbestos and tobacco smoke. Some small-scale studies

were undertaken, but the side effects of BCG were not inconsiderable and the large-scale studies needed to establish efficacy were never undertaken.

A more promising approach is the use of vitamin A analogues, in particular beta-carotene. There are both theoretical and experimental grounds for believing that vitamin A can reduce susceptibility to carcinogens, especially those producing epithelial tumours. Observational studies in humans also give some support to this theory. Several clinical trials have been mounted to test this hypothesis, using patients with treated skin cancer or with cervical intraepithelial neoplasia. Research of this type should be given high priority.

The third approach to reducing susceptibility is based on the assumption that exposure to endogenous estrogen is causally related to breast cancer in females. This hypothesis has a lot of indirect support from epidemiological studies, though it is by no means proven. Drugs which suppress estrogen have been used with great success in treating breast cancer, and it has been suggested that they be used to prevent cancer in women at high risk based on family and reproductive history. This approach is controversial at the present time, but at least one study has been started, and this may become a priority research area in the near future.

EARLY DETECTION OF CANCER

Studies of survival following treatment for cancer of different types consistently show a better prognosis for those treated when the tumour has not spread beyond the organ of origin. Since the paradigm of a progressive spread of disease over time has been widely accepted by clinicians for many decades, localized disease was identified with "early" disease. Both clinicians and health educators accepted as dogma that early detection was beneficial. The logic pushed public health enthusiasts into promulgating mass screening programs in the immediate post-war period. By the early 'sixties, this approach came under increasing criticism. The critics pointed to the possibility of bias in the interpretation of observational studies and stressed the need for randomized trials with mortality, rather than case-fatality, as the outcome criterion.

Table 6 summarizes the results of studies of effectiveness of several forms of cancer screening. The pap smear for cancer of the cervix was introduced before the need for rigorous studies was recognized. Only non-experimental data are available for evaluation descriptive studies of geographic differences in screening intensity and mortality, studies of time trends, and a few formal case-control studies. After reviewing this evidence, a Canadian task force chaired by Dr. R. Walton, concluded

that pap smear screening does reduce mortality from cancer of the cervix, and suggested ways in which screening practice might be made more efficient. Some of these suggestions have not been implemented fully, e.g., frequency of testing, computerized registries to maximize compliance and ensure adequate follow-up, and improved coverage of high-risk groups. These questions require further research.

Early detection of cancer of the breast using physical examination and mammography is one of the few screening methods which has been subjected to randomized controlled trial. The H.I.P. study in New York demonstrated that physical examination and mammography together produced a significant (and important, about 30%) reduction of mortality from cancer of the breast in women aged 50-59. There was no apparent benefit in younger women, and the reduction in mortality in older women was not statistically significant. The implementation of these findings in large-scale demonstration projects in the U.S. was curtailed due to fears concerning the adverse effects of X-rays and some residual concerns about the effectiveness of screening. In Canada, in the early 1970s, the view was taken that no mass screening should be done until further trials had established that mammography added significantly to physical examination in women over 50, and that screening had any effect for women under 50. Eventually such a trial, the National Breast Screening Study, was mounted, but the results will not be available for another few years. In the interval, another randomized controlled trial in Sweden has confirmed the effectiveness of mammography screening, and other European non-randomized studies have also supported this conclusion. Anticipating that the Canadian study will confirm the value of mammography, at least for some age groups, the burning question will be how to implement screening at a reasonable cost. Research topics which could be addressed in the interim include the value of selective screening, the quality of mammography in various settings, and the logistics of screening outside of the main centres.

Although it is widely advocated, breast self-examination (BSE) has not been shown to be effective in reducing mortality from cancer of the breast. At this stage, it seems unlikely that it will be tested in a randomized trial, at least in any developed country. BSE falls under the heading of interventions aimed at increasing awareness of early symptoms. Others include self examination of the testicles and the skin, and early reporting of symptoms such as change in bowel function, bleedings, etc. These interventions form part of many cancer education programs and might logically be included in any national cancer prevention pro-

gram. There will certainly be many who would press for their inclusion. Some form of evaluation of their effectiveness is therefore a research priority, although it will be a challenge to the methodologists to design such studies.

One randomized study of sigmoidoscopy demonstrated a significant reduction in mortality from colorectal cancer, but the numbers of deaths involved were small. Based largely on this finding, and on studies showing the comparability of sigmoidoscopy and testing for occult blood, the Canadian task force on the periodic health examination, chaired by Dr. W.O. Spitzer, included colorectal cancer as a target site for early detection using occult blood tests, but identified it as a high priority for further research. Some randomized trials have been mounted, but it seems doubtful whether they will be completed. There are many technical difficulties. Nevertheless, this remains a research priority, since the potential gains are large.

Randomized trials of chest x-ray and cytology in screening for cancer of the lung have been disappointingly negative. Figure 2, which shows the potential number of lives which could be saved in a population of a million males and a million females if all cases had the case-fatality rate of those presenting with a localized tumour, shows that, despite its overall poor prognosis, lung cancer is one of the three sites with the greatest potential.

The others are breast and colorectal cancer. The figure for cancer of the cervix is, of course, a residual estimate since most cases are already detected before invasive cancer develops. Stomach, ovary and prostate are sites for which the development of new methods of early detection would be of benefit.

SUMMARY OF RESEARCH PRIORITIES

Table 7 summarizes the priorities suggested by the above review. For each preventive strategy, the known targets are listed together with an indication as to the current need for research, depending on what is already known. Some potential targets need to be established in terms of causal relationships and practical importance.

The Table does not capture some of the important overall issues surrounding the development of a coherent cancer prevention program, such as who should coordinate it, at what level it should be organized, and whether it should be a single package or a series of independent interventions. Some of these urgent questions of overall strategy might possibly be answered by suitably designed demonstration projects which would also incorporate some of the detailed research priorities listed in the Table.

Figure 1 – MODEL FOR CANCER CONTROL

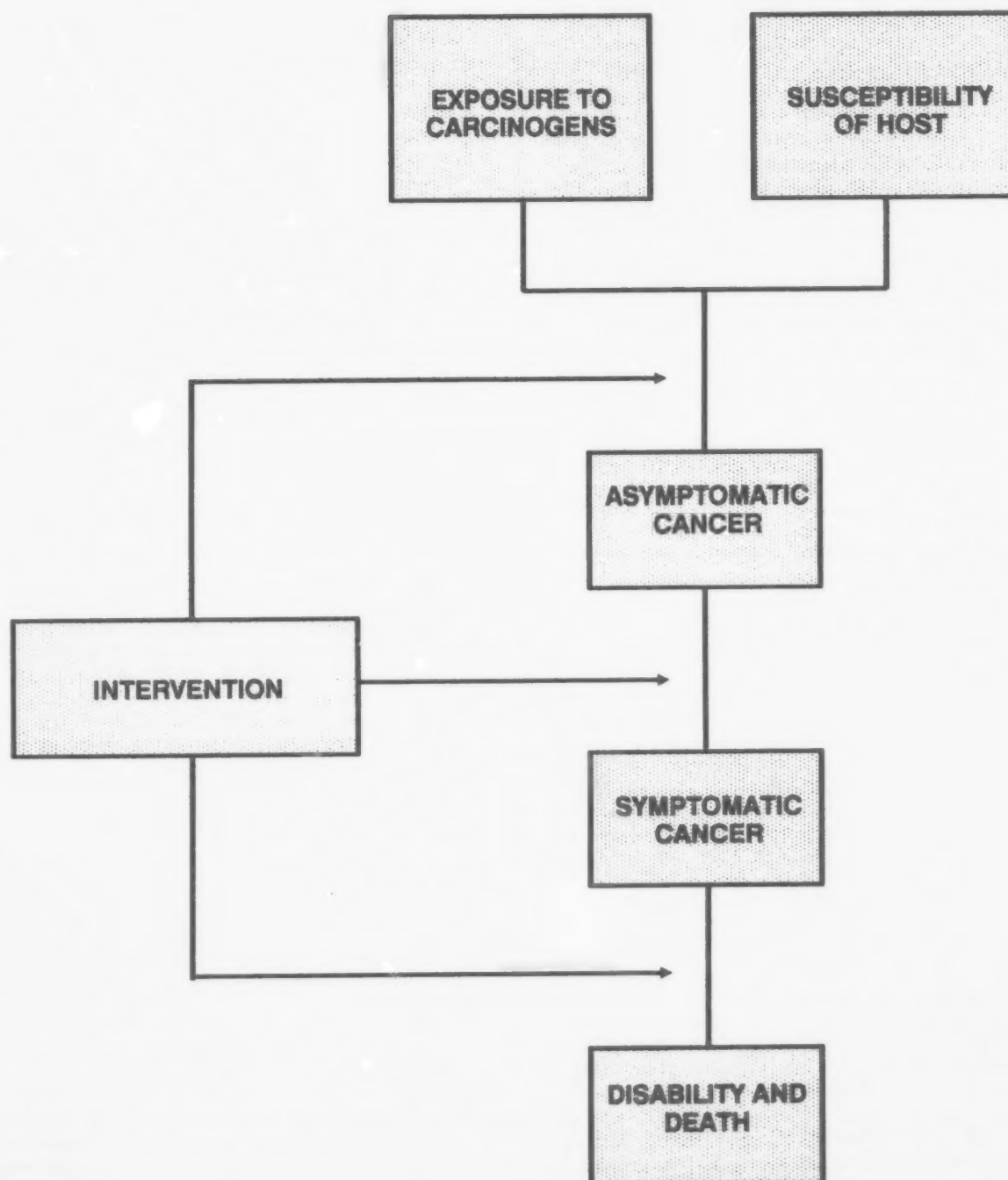


Table 1 — PHYSICAL CARCINOGENS

AGENT	EXPOSURE	SITES
Ionizing Radiation	Occupation Medicine Fall-out	All sites, especially skin, breast, thyroid Lung, leukemia
Ultraviolet Light	Occupation Sunbathing	Skin, lip
? Heat/Trauma	Pipe-smoking Hot food	Lip, tongue Esophagus
? Electromagnetic Radiation	Residential Occupation	Leukemia

Table 2 — CHEMICAL CARCINOGENS

AGENT	EXPOSURE						SITES
	OCC	MED	AIR	WATER	FOOD	BEV/ TOBACCO	
Arsenic	◆	◆		◆			Skin, lung, liver
Asbestos	◆		◆	◆		◆	Lung, pleura, peritoneum
?Cadmium	◆						Prostate
Chromium	◆						Lung
Nickel	◆						Nose, lung
?Alcohol						◆	Mouth, esophagus, liver
Alkylating Agents	◆	◆					Leukemia
Aromatic amines	◆						Bladder
Benzene	◆						Leukemia
Polycyclic HC	◆	◆	◆		◆	◆	Skin, respiratory system, upper G.I. system, urinary system
Vinyl Chloride	◆		◆				Liver
Mycotoxins					◆		Liver
Nitrosamines/ Nitrites					◆	◆	Stomach
Estrogens		◆					Uterus, vagina, liver
Androgens		◆					Liver
Immunosuppr.		◆					Lymphoma
?Lipids					◆		Breast, colon
?Pesticides	◆						Lymphoma

Table 3 — BIOLOGICAL CARCINOGENS

AGENT	CONDITION	SITE
Dominant genes	Retinoblastoma Wilm's Polyposis	Eye Kidney Colon
Recessive genes	Fanconi Anemia Bloom Syndrome Ataxia Telangiectasia Xeroderma Pigmentosa	Leukemia Leukemia Lymphoma Skin
Chromosomal	Down Syndrome	Leukemia
Virus	Epstein-Barr HIV ?Herpes Type 2 ?Papilloma Virus	Lymphoma, ?nasopharynx Skin Cervix Cervix
Schistosoma	Schistosomiasis	Bladder
?Endogenous hormones		Breast, uterus, prostate
?Endogenous metabolites		Colon

Table 4 — TYPES OF CANCER SITES ASSOCIATED WITH KNOWN CARCINOGENS

SITES	% CASES	%DEATHS	KNOWN EXOGENOUS CARCINOGENS		
			PHYSICAL	CHEMICAL	BIOLOGICAL
CONTACT EPITHELIA	46	34			
Skin			+++	+	-
Upper G.I.			+	++	?
Upper R.T.			+	+++	-
Cervix and vagina			?	+	?
Penis			-	-	?
EXCRETORY EPITHELIA	17	21			
Colorectal			+	?	-
Liver, G.B.			+	++	?
Kidney, bladder			-	+++	+
SECRETORY EPITHELIA	27	31			
Pancreas			-	+	-
Breast, uterus, ovary			+	?	-
Prostate, testis			-	?	-
Endocrine glands			+	-	-
NON-EPITHELIAL	10	18			
Brain and N.S.			-	?	-
Bone and C.T.			+	-	-
Lymphatic and haem.			+	+	?

Table 5 — RELATIVE IMPORTANCE OF KNOWN CANCER CAUSING FACTORS

Factors	PERCENTAGE OF ALL CANCER DEATHS
	Best estimate
Tobacco	30
Alcohol	3
Diet	35
Food additives	<1
Reproductive and sexual behaviour	7
Occupation	4
Pollution	2
Industrial products	<1
Medicines and medical procedures	1
Geophysical factors	3
Infection	10?

Source: Doll and Peto

Table 6 — EARLY DETECTION

SITE	METHOD	PROOF OF EFFECTIVENESS
Cervix	Pap Smear	+/-
Breast	P.E. and Mamm. B.S.E.	+ ?
Colon	Sigmoidoscopy Occult Blood	+ ?
Lung	X-ray Cytology	- ?

Figure 2 — POTENTIAL MORTALITY REDUCTION BY EARLY DIAGNOSIS

(Pop. 4 million Males + 1 million Females)

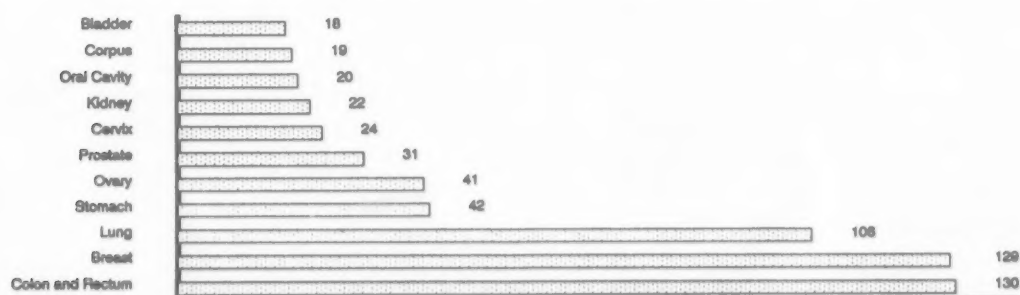


Table 7 — RESEARCH PRIORITIES

PREVENTION STRATEGIES	ESTABLISH TARGETS	QUANTIFY IMPORTANCE	DETERMINE MODIFIABILITY	CHOOSE INTERVENTION	EVALUATE EFFECTIVENESS	OPTIMIZE EFFICIENCY
1. REDUCE EXPOSURE TO CARCINOGENS						
a. Physical						
- Ionizing radiation		♦	♦	♦	♦	
- Ultraviolet radiation						
- Electromagnetic radiation						
- Trauma	♦	♦				
b. Chemical						
- Tobacco:						
- active				♦	♦	♦
- passive		♦	♦			
- Alcohol		♦	♦	♦		
- Diet:						
- fat		♦	♦	♦		
- fibre	♦	♦				
- vitamins	♦	♦				
- nitrosamines	♦	♦				
- Occupation:						
- arsenic					♦	
- asbestos					♦	
- cadmium	♦					
- chromium					♦	
- nickel					♦	
- alk. agents					♦	
- amines					♦	
- benzene		♦				
- poly H.C.					♦	
- vinyl C.L.					♦	
- pesticides	♦	♦				
- Medical:						
- alk. agents		♦				
- poly H.C.		♦				
- hormones		♦				
- immunosuppr.		♦				
- Air:						
- asbestos		♦				
- poly H.C.		♦				
- Water:						
- organo C.L.	♦					
- asbestos		♦				
c. Biological						
- Genetic/						
- chromosomal		♦	♦	♦		
- viruses:						
- E.B.		♦	♦			
- HIV		♦	♦	♦		
- HPV	♦					
2. REDUCE SUSCEPTIBILITY TO CARCINOGENS						
- boost immunity	♦					
- retinoids			♦	♦	♦	
- anti-estrogens	♦	♦	♦			
3. EARLY DETECTION						
- cervix						♦
- breast						
- colorectal				♦	♦	
- lung	♦					
- stomach	♦					
- ovary	♦					
- prostate	♦					
4. INCREASE AWARENESS						
- breast					♦	
- testis					♦	
- skin					♦	

ISCHEMIC CARDIOVASCULAR DISEASE: RISK FACTORS AND PREVENTION

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No highlights have been prepared for this paper. It is one of a set of papers commissioned separately from the literature reviews to suggest research priorities for prevention.

INTRODUCTION

The modern basis of prevention is an understanding of the causes of diseases. In the case of atherosclerosis, the leading cause of death for Canadians and the pathological process leading to ischemic vascular disease (IVD), including heart attacks, strokes and peripheral vascular disease, the causes are multiple and have many interactions. Despite this complexity, there are a few risk factors or causes that are well understood and of key importance. They now provide safe avenues for effective prevention. In the course of undertaking preventive programs, the organized collection of data relating to the effect of the programs on the risk factors and on the incidence of atherosclerotic complications in the population over several years will likely lead to a more complete understanding of the interactions between the disease and the risk factors. This will probably require the measurement of risk factors in addition to those measured in the baseline population survey and should provide the basis for a second generation of better prevention programs. A study of the effects of these programs on the risk factors and the disease should provide further insights and still better strategies for a third generation of preventive programs, and so on until the disease is well controlled. This process will also generate ideas for investigation in animal and clinical laboratories. Conversely, the results of the concurrent basic research may be applicable to further clinical trials and eventually to further population preventive strategies. The correct approach to the prevention of atherosclerotic disease is a broad research program in which public health preventive programs, based on sound scientific knowledge, are implemented in conjunction with scientific observations of their impact on the population. Preventive programs should be revised periodically in keeping with the results of epidemiological, clinical and basic research.

KEY RISK FACTORS

The key risk factors for atherosclerotic disease complications that are confirmed by animal experiments, clinical observations, epidemiological surveys and preventive trials are elevations of serum total cholesterol, triglyceride and LDL-cholesterol (LDL-C), a decrease in serum HDL-cholesterol (HDL-C), hypertension, smoking, obesity, physical inactivity and diabetes mellitus. (Other risk factors that are not as well documented will be mentioned later.) From the studies of diet, by Keys and others, in a number of countries and in metabolic laboratories, it is evident that elevations in serum lipids are caused mainly by excessive amounts of total and

saturated fats, cholesterol and total calories. Other studies show that excessive salt in the diet is a risk factor for hypertension. While there is an obvious genetic influence on serum lipid levels, this does not account for the fact that in Canada the level of serum lipids and the incidence of coronary deaths are much higher than in some other countries. The major cause of the higher serum lipid levels and coronary death rate is obviously our lifestyle. It is in this area that public health preventive programs should be applied.

PUBLIC HEALTH PREVENTIVE PROGRAMS

Public health programs for the prevention of coronary heart disease should attempt to improve serum lipid and lipoprotein profiles as well as carbohydrate tolerance and physical fitness, lower blood pressure, dietary total fat, saturated fat, cholesterol and salt, stop smoking and prevent obesity. In simple terms, this calls for an integrated program of diet, exercise and help for those addicted to tobacco. It is a program to improve the lifestyle of Canadians. It is wasteful to plan separate programs for diet, fitness or smoking. The experts in these three areas should work together in a multiple risk factor intervention. When combined, the three aspects of this program should have a favourable effect on all the key risk factors listed above. The degree to which the customary diet, activity level and smoking habits are to be changed requires the setting of goals by panels of experts in these fields. The extent to which the incidence of coronary heart disease, stroke and other ischemic events will be reduced can be predicted by past (and future) epidemiological data using methods described by Richard Peto and his colleagues. The fact that populations in some countries have almost no deaths from IVD indicates the great potential for saving lives in Canada.

POPULATION SURVEYS FOR BASELINE DATA

Before health preventive programs for IVD are instituted, Canada needs to have good baseline data on the levels of the important risk factors for IVD in samples of our population and on the incidence of morbidity and mortality from coronary, cerebral and peripheral vascular disease. It is unfortunate that up to now there has been no organized attempt in Canada to determine trends in dietary intake and levels of risk factors for IVD by periodic population surveys.

STANDARDIZATION METHODS

In order to carry out these population surveys it is essential that standardized methods be developed for application across the country and for repeat sampling in future years. Without standardized methods the results cannot be compared from one province or one decade to another. Standardization is especially important for laboratory methods for serum lipids and lipoproteins and for collecting and analyzing dietary intake data. In the case of serum cholesterol triglyceride, HDL-C and LDL-C and dietary intake, the methods have been developed but up until now there has been no agreement that they should be generally adopted and applied. The lipid and lipoprotein methods must be standardized with or traceable to the Lipid Standardization Laboratory of the Centre for Disease Control in Atlanta, Georgia, in the same way as are the methods used at the WHO Lipid Laboratory at the University of Toronto. Canadian investigators and granting agencies must realize that there is an extra cost for using standardized lipid methods. Without that extra cost, the data is very likely to be useless for comparative purposes. No one lipid laboratory can possibly do all the work for Canada. A Canadian Reference Laboratory needs to be established in order to standardize regional laboratories in the future. This should also include the development of standardized methods for apolipoproteins AI, AII and B and possibly others. In the future, other lipid risk factors will undoubtedly be proven to be important predictors of coronary heart disease, and they too will require standardization. Standardization needs to be extended to the portable desk-top machines that are being developed for screening populations for hyperlipidemia. So far, this has not been accomplished satisfactorily even though the technology is available.

NEW RISK FACTORS FOR IVD

Already there is evidence of new and important lipid/lipoprotein/ apolipoprotein risk factors for ischemic vascular disease. These include the serum concentrations of apolipoprotein AI and AII that are indices of HDL and negative risk factors, and apolipoprotein B, an index of LDL and a positive risk factor. The ratio of serum phosphatidylcholine to free cholesterol (PC/FC ratio) in serum is a negative risk factor and an index of the saturation of the lipoproteins with free cholesterol and the fluidity of the surface membrane of the lipoprotein particles. The concentration of HDL-triglyceride, unlike HDL-C, is a positive risk factor for coronary heart disease. Sinking pre beta lipoprotein

cholesterol (SPB) that is comparable to Lp (a) lipoprotein is a positive risk factor for coronary heart disease. These risk factors have been recognized more recently and need to be evaluated in epidemiological studies for comparison with the power of total cholesterol, LDL-C and HDL-C to predict coronary disease. If they are confirmed as independent and potent risk factors they can be used in combination with the traditional risk factors as a guide to prophylactic programs that will modify all or most of the risk factors favourably. Even if some of these risk factors, such as SPB, the concentration of which seems to depend almost entirely on heredity, cannot be influenced by changes in lifestyle, they can be used to select target groups and families in the population for more aggressive preventive programs. Persons with very low HDL-C levels appear to be susceptible to increased risk of premature coronary heart disease despite normal or even low total cholesterol levels. This group may require preventive programs that are somewhat different from those aimed at the general population. The identification, investigation and treatment of such groups should be initially undertaken in a clinical setting.

DRUGS

Population groups for special consideration are those on certain antihypertensive and antiarrhythmic drugs, diuretics and oral contraceptives which adversely affect serum lipoprotein concentrations.

The use of serum-lipid-lowering drugs for the prevention of IVD in the general population is out of the question since it is obvious that the majority of Canadians are at extra risk because of deficiencies in lifestyle that can be positively influenced by diet, exercise and energy balance. Nevertheless, health professionals will have to study the question of when to consider the use of lipid-lowering drugs in the group of people who do not respond adequately to conscientious changes in lifestyle. This too should be studied in a clinical setting.

NUTRITION STUDIES

There need to be further animal and clinical studies of the influence of certain nutrients and foods on serum lipid and lipoprotein patterns, carbohydrate tolerance, atherogenesis and thrombogenesis. These should include comparisons of the effect of soluble fibres, starches and simple sugars on carbohydrates and lipid metabolism, the metabolic effects of different fatty acids, including the omega three fatty acids from fish, and the effects of dietary proteins from various animal and vegetable sources. Public health preventive programs using

present knowledge need not wait for the results of these laboratory studies but the new information may be deemed worthy of application in future preventive programs.

BEHAVIOURAL MODIFICATION

Some consideration should be given to better methodology for behavioural alteration in the general population and in special groups such as smokers, drinkers, the obese and the indolent. The methods should include the provision of good examples or role models, encouragement, education, follow-up and reinforcement. Application of these methods in each public health preventive program should be carefully planned and, if possible, standardized. The impact of these methods on comprehension, attitude and adherence to the program by the public should be evaluated periodically in the same way, and possibly at the same time, as population surveys for trends in IVD risk factors, dietary intake and incidence of ischemic vascular disease.

SUMMARY OF THE MAJOR RESEARCH PRIORITIES

1. Population surveys of the levels of IVD risk factors, incidence of IVD and dietary intake are needed now as baseline data for future studies of the impact of public health programs for the prevention of IVD.

2. Public health programs for the prevention of IVD should begin immediately and should have as objectives the improvement of serum lipid and lipoprotein profiles as well as carbohydrate tolerance and physical fitness, the lowering of blood pressure, dietary and saturated fat, cholesterol and salt, the prevention of obesity and the cessation of smoking. This should be accomplished by means of a single integrated program of diet, exercise and help for those addicted to tobacco.

3. Standardized methods need to be established for the determination of serum lipid and lipoprotein concentrations and the collection and analysis of diet intake data.

4. A Canadian Reference Laboratory for lipids, lipoproteins and apolipoproteins needs to be established for the preparation of reference material and the standardization of regional laboratories.

5. Population surveys of the levels of the IVD risk factors, the incidence of IVD and dietary intake should be repeated periodically in order to evaluate the impact of public health preventive programs and to plan for their improvement.

6. Succeeding generations of population surveys should evaluate the IVD risk factors that have been recognized more recently and compare them with the traditional risk factors.

7. Succeeding generations of public health preventive programs should consider modifications of the programs to include new evidence concerning the effect of diet and exercise on the cardiovascular disease risk factors and on atherogenesis.

PUBLIC HEALTH PROGRAM DEVELOPMENT AND CARDIOVASCULAR DISEASE PREVENTION

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No highlights have been prepared for this paper. It is one of a set of papers commissioned separately from the literature reviews to suggest research priorities for prevention.

CARDIOVASCULAR DISEASE IN CANADA

Cardiovascular disease (CVD) is by far the most common cause of death and disability in Canada today. It accounts for approximately one-half of all deaths, about two-thirds of these due to ischemic heart disease (IHD) and one-fifth to stroke. Roughly two-thirds of heart attacks result in sudden death (i.e., less than thirty minutes) and approximately one-fifth of first-time events leading to death occur without warning or previous symptoms. Under these circumstances, treatment as a course of action is not feasible. Clearly, prevention is the only realistic hope for these individuals. Mortality among survivors of heart attacks is high, with an annual mortality rate about five times that of those free of disease in comparable age and sex groups. Once vascular disease of this type has become established with clinical symptoms evidence, the disease process is far advanced. Under such circumstances treatment regimes are bound to have only limited success.

CVD presents a significant economic burden to this country, with substantial financial implications for the health care system. CVD diagnoses account for approximately 7.4 million hospital days annually and 25% of all disability pensions paid out under the Canada Pension Plan.

There are wide disparities between and within populations with respect to CVD mortality. Death rates vary from country to country. In Canada, the death rate is about twice that of France and five times that of Japan. It is highest in eastern Canada and lowest in the West. CVD mortality rates vary substantially with the level of education and income, people in the lower end of the scale having the highest rate.

Rather dramatic secular changes have been occurring in CVD mortality rates. After a prolonged increase, death rates from IHD declined approximately 30% between 1969 and 1982. This has been true for all age and sex groupings. The decline in stroke mortality has been even greater. Despite these rather impressive rates of decline, CVD is still the leading cause of premature death (less than 65 years of age) for both men and women, with a high absolute number of deaths occurring annually.

The facts presented above are some of the important reasons justifying primary prevention of CVD, which is underscored by the mass nature of this disease in our society. Much of this disease can be prevented, or at least postponed, since it is attributed in large measure to individual personal behaviours and the influence of the community or social environment. The dramatic changes in mortality rates which have occurred over the past two decades underscore the potential for primary prevention.

There is a strong ecological as well as individual relationship between the various risk factors for CVD and disease rates. These relationships have been suggested not only by clinical observations, but also by biologically acceptable mechanisms of causation. The risk factors producing independent influences on CVD rates are hypertension, elevated serum lipids, and cigarette smoking. Other related and important factors include obesity, sedentary lifestyle, and diabetes. It has now become well accepted that the reduction of risk factor levels through educational and clinical strategies will reduce risk and, ultimately, disease incidence. It has been adequately demonstrated that programs which encompass risk reduction strategies of this nature are desirable, feasible and safe on an individual as well as a population basis.

Because the prevalence of risk factors for CVD has been estimated to be very widespread in this country, virtually the entire population (whole communities) should be targeted for risk-reduction strategies. In the past, efforts have concentrated largely on people with the highest risk of disease or highest elevation of risk factors. Rose and others have aptly demonstrated the need to target the population at large for risk reduction, not only because the risk factors are widespread, but also because most of the disease comes from the middle of the population distribution, that is, the group with small to moderate elevation of risk. If programs are to have a major impact on the prevalence of CVD in our society, individuals in this group as well as those at the upper end of the risk distribution must be targeted for intervention.

On an individual basis, it is well known that a high elevation of one risk factor can significantly increase the risk of CVD. It is not as well appreciated, however, that mild to moderate elevation of a number of risk factors can likewise contribute to a significantly high risk. Consequently, CVD prevention calls for a multiple risk factor approach, in contrast to many of the single risk factor approaches now employed. This kind of programming would reflect and address the nature of CVD risk more directly and, theoretically, should be more efficient.

RESEARCH ISSUES

If one accepts that CVD is a major public health problem which warrants a public health response, it becomes clear that there are a number of barriers to be overcome if appropriate programs are to be implemented. It is recognized that this programming would most likely take a two-pronged approach, that is, use a high risk strategy in conjunction with a population strategy. This type of

programming, directed towards chronic disease and operating through the public health system, does not presently exist in Canada, particularly at the provincial level.

In conducting broad community-based programming, an adequate database is essential for properly assessing and defining the problems at a community level and establishing priorities (performing a community diagnosis). With this data, sub-groups (target groups) could be identified in order to specifically address geographic or socioeconomic disparities. This type of information is necessary for program development and implementation.

The other major purpose of the database is to provide a reference point or benchmark to monitor change over time. This information is essential for program evaluation.

At the present time in Canada, there are many knowledge gaps in our database. The most glaring is probably the lack of incidence data with respect to CVD. Lack of data of this type severely hampers program development and evaluation. Although it is well recognized that the CVD mortality rate is falling, there is no data to confirm whether this represents fewer events or increased survival following an event. Through the use of computer linkage, the Nova Scotia-Saskatchewan Cardiovascular Disease Project has demonstrated the feasibility of determining incidence on a pilot basis. More research is needed to make this approach, or perhaps others, operational, at least at the provincial level, utilizing routinely collected data (hospital separation, death certificate).

Mortality data for CVD is presently available in Canada and is readily accessible. However, this data is somewhat out of date when published (only 1982 available now). Considering the current trends in CVD mortality, more up-to-date published data should be published and made available on a routine basis.

Provincial and national risk factor data for CVD is presently available from such national surveys as the Canada Health Survey, the Canada Fitness Survey, and the Nutrition Canada Survey. These databases are old and their methodologies yielded results that cannot be compared. Additionally, they were not designed specifically to determine risk factor levels for CVD, although some of this information is available. Sample sizes were not large enough to permit this data to be widely used on a provincial basis. Nova Scotia currently has the only population sample of CVD risk factor data available in the country, collected through the recently completed Nova Scotia Heart-Health Survey.

For public health programming, periodic risk factor surveys (such as the Nova Scotia Heart-Health Survey) are essential for program development and

evaluation. It is important that the methodologies used to collect this data be of high quality and utilize standardized methods, so that results can be compared over time and between national and international jurisdictions. At the moment, there is marked variability between laboratories with respect to lipid determination. Research efforts should be directed towards establishing methods of standardization and quality control for these laboratory procedures, which would be suitable for adoption by hospital laboratories from both a technological as well as a financial perspective. With further research, data collection could be standardized in areas such as questionnaire design and anthropometric measurements.

Nutrition is a very important area for research to further the development of public health programs directed toward CVD prevention. One of the basic approaches to public health programming would be to establish a dietary strategy which addresses, in specific terms, issues surrounding dietary fat consumption and energy balance.

At the present time there is no general consensus, particularly in the nutrition community, on what should constitute the Canadian diet with respect to CVD. Consensus on these issues is needed. Before programs can be implemented to attempt to restructure the dietary intake of the population, the present consumption patterns of Canadians, translated into measurable amounts of macro-nutrients, must be determined. Although the literature is replete with information on the reliability and validity of various nutrition data-collection instruments to do this (e.g., food frequency methods, 24-hour recall methods), there is a lack of an up-to-date nutrient file which accurately reflects the nutrient composition of foods on a regional or national basis. Without this type of accurate nutritional nutrient information, it is extremely difficult to develop appropriate nutritional programs to target CVD prevention and to track changes in the consumption of specific nutrients over time (e.g., monitoring the change in consumption of saturated fat as a percentage of calories over time in response to a program design to reduce fat consumption).

Finally, clear nutrition concepts must be defined in order to explain the CVD diet to people. At present, it is virtually impossible for the average individual to translate present heart-healthy dietary information into actual food purchases. For the population to do this, certain environmental changes, involving the agricultural and the food service communities, have to occur to meet the appropriate demands of the public with respect to heart-healthy foods. In conjunction with this change, a "Canada's Food Guide" which speaks specifically to a heart-healthy diet, in the context of maintaining energy balance, is required. Research to develop this informa-

tion has to be undertaken. Until it is available, public health programming in the field of nutrition related to CVD will be greatly hampered.

It is well recognized that CVD begins in infancy. The pathological processes of atherosclerosis which underline this disease begin very early in life and anatomical lesions are demonstrable in a substantial portion of the population in the second and third decade of life. The behavioural patterns associated with CVD (diet, exercise and smoking) are usually adopted early and persist into adult life. At the present time, there is no consensus with respect to criteria for determining CVD risk in children. Research must be done to arrive at a consensus on questions such as the following: What is hypertension and hypercholesterolemia in children? Who should be screened, for what, and when? At what level should treatment be instituted?

There is no consensus as to what constitutes a heart-healthy diet for children, particularly with respect to the level of fat and to cholesterol intake. Research and consensus on these issues are extremely important if public health programs are to be designed for addressing and preventing the development of unhealthy lifestyles associated with CVD in children.

As has been mentioned earlier in this report, CVD is far more common in individuals of lower

socio-economic status. From a public health perspective, reaching these individuals presents many difficulties. The public health system has a long history of community programs directed at these groups. Child and maternal health programs, for example, have been operating in most public health departments for many decades. One of the major difficulties encountered in delivering these programs is trying to reach the individuals who need the programs the most.

This type of problem will likely exist with the delivery of CVD prevention programs, particularly to disadvantaged groups within society. It is not yet clear what methods should be used to reach these individuals and effect the desired behavioural changes. These questions must be answered if this type of programming is to be successful. Research into this area is of prime importance, particularly in light of the fact that no single solution will likely be found. On the contrary, a mix of strategies will probably be required, varying from region to region in the country and depending on the ethnic/social make-up of each region. It is probably in this latter area that it will be most difficult to find solutions. However, success in this area will have significant long-term impact on the incidence of disease.

PRIORITIES FOR RESEARCH IN DRUG PROBLEM PREVENTION

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No highlights have been prepared for this paper. It is one of a set of papers commissioned separately from the literature reviews to suggest research priorities for prevention.

PREMISES

1. Most of the research on illicit drug use and its prevention has been conducted in the United States, where drug use may, indeed, be "epidemic". In terms of the availability and incidence of use of various drugs, as well as the history and demographic characteristics, the generalizability of U.S. research to the Canadian context is very limited, and we must not rely on it uncritically. My statement is based more broadly on the prevention literature, including that relating to alcohol, and on the social psychological literature on attitude and behaviour change.

2. An effective prevention strategy must be based, in part, on an adequate understanding of the etiology and natural history of the "disorder". Thus, I will be pointing to several issues in these areas, particularly as they impact on prevention.

3. *Prevention concerns* focus upon health promotion and disease prevention, rather than upon addiction itself. In the area of illicit drug use, we must be concerned with hazardous or health-risk patterns of use, perhaps related, for example, to possible immunosuppressant effects of marijuana, pulmonary diseases from marijuana smoking, mental and physical effects of amphetamine use by students and truck drivers (including the risks of accidents), and, of course, the significant risks of hepatitis and AIDS from shared needles. One must also be concerned with the use of black-market substances of unknown composition, unknown adulterants and indeterminate dose levels.

4. Unlike alcohol and tobacco, the use of the drugs discussed here (including amphetamines, barbiturates, psychedelics, solvents, cocaine and opiates) is illegal. By limiting supply, law enforcement, if effective, can be one element in prevention. However, one cannot easily develop programs which promote responsible or less risky patterns of use of illicit substances, although such strategies may well be rational in other terms. Further, by creating the need for black-market criminal activity and deviant drug subcultures, the present laws may create or intensify other drug-related problems. The issues are extremely complex and contentious, and cannot be addressed in this paper. Thus, we will assume that prevention must be approached within the framework of existing laws. Nonetheless, it may well be useful for researchers to examine alternatives for approaches to prevention through the law, such as the limited "decriminalization" of marijuana now in effect in several states in the U.S. and in the Netherlands.

KEY PRIORITIES

1. *Research on concurrent multiple drug use.* A voluminous literature has established the reality of concurrent multiple drug use as the rule, rather than the exception. Heavy users of one drug (including alcohol, cigarettes, marijuana) tend to be frequent users of a range of other drugs. Users of the "hard" drugs, such as cocaine, amphetamines and heroin, tend to be users of multiple other drugs, and to use those drugs heavily. We need more research to map out the patterns of multiple drug use, to determine the health risks inherent in acute and chronic drug interactions, and to determine the extent of a general drug-taking disposition.

The extent of concurrent multiple drug use also indicates that prevention might be directed more broadly to drug use per se. It also suggests that prevention campaigns directed toward one drug, such as alcohol or marijuana, should, if successful, have an impact on the use of other drugs as well. I know of no research that has specifically addressed this problem (and this opportunity).

2. *Research on the relations between drug use and other behaviours.* Some research has emerged in the past decade which studies commonalities among the use of various drugs and other, possibly functionally equivalent behaviours. The data do not support the assumption of a unifactorial model of health-related behaviours. However, there may well be a subset of behavioural problems with common roots, perhaps described as excessive or compulsive, and perhaps related to environmental factors, personal dynamics or brain biochemistry. It has become common for people to be described as "addicted" to patterns of behaviour as disparate as eating junk food, watching television sports, exercise, gambling and even over-working. Again, this suggests that prevention strategies may be directed toward classes of similar or equivalent behaviours, and that strategies which simply seek to "prevent" one such behaviour may lead to the substitution of another behavioural pattern which is equally problematical.

3. *Research on the identification and understanding of high-risk groups.* Research has identified certain groups at risk. Some are identified in terms of demographic or occupational characteristics, for example, low socio-economic status (SES), some ethnic or immigrant groups, unemployed people, and students and truck drivers (particularly amphetamines). Others are defined in terms of family or genetic background, for example, those with a family history of drug abuse, crime or depression. Still others are defined by a stage of life, for example, people going through a major life transition, such as the first year of high school or

university, or a marital separation. Studies also suggest that women are prescribed psychoactive drugs more often than men, and that they also may be relatively more vulnerable to the physical consequences of alcohol and other drug use. We need more research which identifies and explains various forms of high risk, and which documents the short-term and long-term risks. For example, Newcomb at UCLA and others are beginning to publish reports of longitudinal research which assesses the consequences of adolescent drug use in the third decade of life. We also need more research on how environmental factors contribute to the problem, for example, on the impact of unemployment or underemployment, and on the role of social support in "buffering" the stresses which may lead to drug problems. This research is needed to develop directed primary and secondary prevention strategies in relation to these high-risk groups, particularly to reduce or attenuate the risk during vulnerable periods.

4. *Research on the cognitive processes underlying attitudes and decisions about drugs.* The paper Achieving Health for All is a well-structured and well-reasoned presentation of what is, indeed, a "new vision" of health. My major problem with it is its implicit assumption that health-related behaviours are the outcomes of conscious, reasoned decisions by individuals and communities. In the light of contemporary social psychological research and theory, the report is a bit too optimistic (if not Pollyanna-ish) about the applicability of rational health-decision models, and about the ability of attitude-change programs to improve the situation.

Contemporary social psychology focuses on the basic cognitive processes which underlie social behaviour, particularly those which involve "automatic" thinking in terms of schemas and prototypes, and on the associated processes of attention, memory and decision-making. In the area of health-related decision, Janis and others have criticized rational decision-making models. In particular, behaviours such as drug use have such powerful immediate reinforcement that rational consideration of the long-term adverse consequences, even to the point of being self-destructive, may be beside the point.

Petty and Cacioppo have proposed the elaboration likelihood theory of attitude change, a model which is highly influential in the field today, and likely the wave of the future. In this model, attitude change is described as occurring through central or peripheral routes. Central route change involves actual argumentation and stimulates thinking and conscious decision-making by the audience. It tends to be relatively enduring, but, because it demands involvement and effort to process the information, it is relatively rare. Most attitude

change occurs through the peripheral route, involving non-issue-relevant factors such as social desirability, source attractiveness and other cues.

Peripheral route change tends to be relatively superficial, and persists as long as the relevant cues remain available and salient. However, peripheral route change may become enduring if the behaviour change causes people to think more favourably about the issue and to find reasons to "bolster" their behavioural choice.

In the area of drug use, my suspicion is that we began to turn around the cigarette-smoking problem when the message was changed from health dangers (central) to one which bolstered the social undesirability of public smoking (peripheral). A couple of recent studies show changes in the schemas held by people about smoking and (more importantly) smokers. Drug users often appear to be relics of the 1960s. In any case, research should make a clear distinction between the two processes of attitude change, and evaluate the effectiveness of each and the possibilities of engaging the individual in conscious decision-making about health in general, and about drug use in particular.

5. *Evaluation research on drug education.* Drug education has become a part of high-school life, and significant resources continue to be devoted to it. Yet the literature is far from convincing about the utility of these programs. Is drug education really effective? Such a question cannot be answered because it ignores three important complications: the many different educational strategies employed, the many different effects possible on various attitudes, skills and behaviours, and the fact that the effects may vary considerably with different subgroups of adolescents, defined in terms of age, social class, ethnicity, sex, urban or rural environment and involvement with various drugs. Indeed, some of the better evaluation studies done recently show clearly that there are complex interactions among the strategies used, the subpopulations on which they are used and the results obtained.

Since drug education remains a major thrust of primary prevention, more and (especially) better research should be conducted in this area. This research should not be primarily in the area of designing new strategies or techniques; rather, it should focus on much more fine-grained and long-term evaluation of these techniques. Then, perhaps, we can begin to develop more effective, targeted approaches.

6. *Research on drug problems in the workplace.* The overwhelming majority of studies on drug-use etiology and change have been conducted with high-school and post-secondary students and with clinical samples of addicts. Relatively little is known of drug-related problems in other populations, particularly workers in factories, offices and other settings. We know enough about drug use in the workplace to know that it is a significant prob-

lem of safety and productivity as well as of health, and that employment-based programs, particularly secondary prevention programs (Employee Assistance Programs, or EAPs) can be remarkably successful. Much more research should be directed

toward this population, to better define the nature and risk potential of the problems, to understand the causes (including the nature and stresses of work itself), and to develop and evaluate properly programs of primary and secondary prevention.

KNOWLEDGE GAPS IN THE AREA OF CARDIOVASCULAR DISEASE

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No highlights have been prepared for this paper. It is one of a set of papers commissioned separately from the literature reviews to suggest research priorities for prevention.

RISK FACTORS

There is a continuing need for research into risk factors for cardiovascular disease, even though we have enough knowledge now to enable useful intervention. The areas which deserve ongoing exploration include: the clarification of "minor" risk factors, the search for as yet unidentified risk factors, the role of individual susceptibility, risk factors in children, and methods of risk factor modification.

"Minor" Risk Factors: In addition to the major risk factors that have been established beyond reasonable doubt (cholesterol elevation, hypertension, smoking and diabetes), other risk factors are not yet as well accepted and are often viewed as "minor". These include low physical fitness level, obesity, abnormal levels of psychological stress (including unemployment, job disruption) and softness of the water supply. Recent assessment of the role of physical fitness, published by the U.S. Centers for Disease Control, reveals that the importance of this factor may be underestimated and warrant recognition as a "major" risk factor. The problems which precluded earlier acceptance of the role of physical fitness were poor research design and difficulties in measurement. The same problems are encountered in the study of obesity or, more broadly, the role of nutrition, where measurement is a major difficulty (especially in contrast to measurement of the accepted "major" risk factors).

Search for Unidentified Risk Factors: Although we already have enough information on risk factors to justify intervention efforts, the fact remains that most of the variation in outcomes (i.e., morbidity and mortality) remains unexplained. Some of this may be resolved by more accurate study of both major and minor risk factors (especially with regard to measurement), but it is fully plausible that additional risk factors may exist. These are likely to be at a finer level of discernment than we are currently practicing in epidemiological studies (e.g., various lipid fractions, cholinesterase, factor VIII activity, plasma fibrinogen, ratio of essential to saturated fatty acids and genetic markers) and will necessitate a closer and more timely relationship between population epidemiologists and their clinical and laboratory research colleagues.

Individual Susceptibility: The issue of individual susceptibility has its roots in a clinical question: Why did this patient develop this disease at this time? This is an aspect of unexplained variation that needs more attention. Epidemiology studies populations defined in various ways that must inevitably lump individuals and potentially relevant subgroups, thus losing sight of "explanations within explanations". Examples of this include the

evidence of salt sensitivity in a minority of the population for whom (in particular) salt reduction would have much greater impact with regard to hypertension, and the relatively greater importance of abdominal obesity over lower body obesity (which appears to be genetically determined) with regard not only to the probability of hypertension but also to longer term mortality experience. Again problems of measurement arise, such as the difficulty of obtaining an accurate dietary history and the challenge of investigating "dynamic" rather than "static" risk factor profiles.

Risk Factors in Children: This area is generally not well explored. Although it is known that hypertension and obesity in childhood tend to "track" into adult life, and that many lifetime habits are initiated in these years, little is understood about the actual relationships and most of the research is on the adult population. Yet if we are to adequately address the potential for primary prevention, more attention to the early years would appear warranted.

Methods of Risk Factor Modification: Medical education is very sound in the area of pathophysiologic diagnosis and is becoming strong in recognizing the role of multifactorial etiology which leads to most of the diseases and disorders seen in the latter part of the twentieth century. Where disease can be effectively addressed through the use of drugs, medicine also performs well, but the same cannot be said of lifestyle modification. Physicians and other clinicians need further education in lifestyle modification. For this to come about we need to educate talented clinician-researchers and attract them to this area, increase its esteem (and therefore perceived importance), develop techniques and implement them. At present, many clinicians are able to make a crude behavioural diagnosis but are neither knowledgeable nor very effective in influencing at-risk behaviour in a positive direction. As for cardiovascular disease, the prime areas of research would appear to include smoking cessation, compliance with drug therapy, stress management, nutrition and fitness counselling. Finally, research and practice in the area of behaviour modification needs to be suitably multidisciplinary.

BROADER ISSUES

In addition to further studies into risk factors, there are a number of broader issues that require examination: further comparative studies of cardiovascular disease incidence and prognosis, baseline studies of risk factor distribution at provincial and local levels, the need for more public health, work-site- and school-based intervention programs and de-

monstration projects, the development of primary health care strategies (including the role of the family physician), and public policy research and development in the broader realm of health promotion. These questions are interrelated and are all relevant to the need for economically and epidemiologically sound complementary strategies for addressing the needs of those at high risk of disease as well as the population as a whole whose larger numbers of lower-risk individuals will contribute most of the eventual caseload.

Comparative Studies of Incidence and Prognosis: Canada has pioneered in the development of records linkage techniques culminating in the development of GIRLS (generalized iterative records linkage system). This system and complementary records linkage capabilities at the provincial level have enabled the Nova Scotia-Saskatchewan Study Group to differentiate incidence from episodes of acute myocardial infarction (AMI) and to attach a prognosis to each event (fatality:case ratio). Such a capability (demonstrated but not yet published) means that we can infer with greater reliability how much of the decline in population mortality from AMI is due to decline in incidence (essentially a function of primary prevention) and how much is due to improved prognosis (mainly a function of treatment). The capability thus exists to establish a baseline for intervention policies and programs, to monitor trends and to evaluate progress. Now that the Nova Scotia-Saskatchewan Study has been effectively piloted, consideration should be given to extending this approach to other areas of the country.

Baseline Studies of Risk Factor Distribution: At present only Nova Scotia has adequate current (1986) baseline data on cardiovascular risk factor prevalence. Information is also available on a variety of other attitudinal and behavioural factors relevant to cardiovascular disease. This type of data should be available in all provinces as a prerequisite to effective provincial strategies for health promotion and risk factor intervention. Previous national surveys do not provide adequate data for provincial-level analysis in most provinces, but more adequate national surveys could be designed to achieve this if the budget were sufficient to permit optional sample sizes and response rates. A more collaborative federal-provincial approach to promote and carry out such surveys might be worth consideration.

Public Health, Worksite- and School-Based Intervention Programs and Demonstration Projects: Provincial and local health departments have a general mandate to address the prevention and control of chronic diseases, including cardiovascular disease, but only in a few instances can one illustrate programs developed or planned. There is need for more innovation, especially in light of the federal Achieving Health for All document, and

National Health Research and Development Program (NHRDP) money should be earmarked to promote effective demonstration projects. The same holds true for the worksite and in the context of school populations. In the latter instance, public health agencies are often able to take a lead, but in the former, there is a need to stimulate interest and activity through occupational health programs. Cardiovascular disease and associated risk factors are skewed across the socio-economic spectrum, and blue collar workers are at highest risk.

The Development of Primary Health Care Strategies: Studies in Montreal (Battista, Pineault) and the recent Ontario report (Evans) indicate that there are serious flaws in the fee-for-service approach to medical care. Salaried/sessional physicians have been found to devote more time to prevention. This illustrates the current inertia in medical practice patterns with regard to adopting widely recognized prevention activities (e.g., Task Force on Periodic Health Examination). This could be overcome by adjusting the fee schedule and/or encouraging a shift towards salaried practice. Neither of these are likely to be politically easy to do, but if we are serious about increasing physician participation in the prevention effort (a critically important element), incentives are needed. Demonstration projects again may be a useful tool, especially to increase the linkage between medical practice and public health efforts. Family physicians are the most obvious group for this type of collaborative focus.

Public Policy Research and Development: There are many areas of policy research that are undoubtedly already being assessed by Health and Welfare Canada, so I will focus only on one of these—the need for studies to define efficiency cut-off points for the implementation of complementary high risk and population-based approaches to cardiovascular disease prevention. At present, cholesterol is of utmost priority, but some reference can also be made to blood pressure and obesity/overweight. The population targets of lifestyle modification (e.g., fitness, nutrition, smoking, stress management) are not unique to only one given outcome but can be expected to benefit a whole range of outcomes (e.g., cardiovascular, respiratory, musculoskeletal, psychological). This endeavour needs therefore to recognize a broad range of potential benefits.

PRIORITY AREAS

Stemming from the above discussion, a number of broad research questions can be identified, answers to which can be expected to benefit the

development and implementation of policies and programs.

Question 1: *How much more variation in cardiovascular disease outcomes can be explained through further investigation into risk factors?*

Research in this area should cover the following: further clarification of existing risk factors, discovery of new risk factors (not yet identified), investigation into the phenomenon of individual susceptibility, study of risk factors in children, and methods of risk factor modification.

Benefits to program and policy development include the potential to increase the scientific legitimacy of health promotion efforts in the area of so-called "minor" risk factors (e.g., physical fitness, obesity/overweight, stress management), new intervention initiatives based on additional risk factors, improved clinical assessment of at-risk individuals, better-formulated policies for children and youth, and improved approaches to risk factor modification.

Question 2: *Can we improve our methods of cardiovascular disease surveillance using epidemiologically sound and efficient methods?*

The purpose here is to be able to identify cardiovascular health status, compare regions and population groups, assess needs and evaluate progress in prevention and prognosis. With records linkage techniques and modern survey methods, applied research along these lines can be highly cost-effective.

Benefits in this area are related to the principles of efficient policy and program design (i.e., population data-based planning and evaluation).

Question 3: *Can innovations in intervention methods be stimulated?*

The problem to be addressed here is the inertia in much of public health and medical practice, which need to become reoriented towards the prevention of chronic disease on a larger scale and with approaches that are better organized. Demonstration projects, including the development of both worksite- and school-based programs and experimental approaches to remuneration systems for practitioners, should be given higher priority.

The benefits in this area lie at the heart of the whole issue of cardiovascular disease prevention and, more broadly, health promotion and lifestyle modification. We will succeed in reorienting health services (as advocated in *Achieving Health for All*) to the extent that we can modify the priorities and practices of health departments towards a broader

concept of public health and enhance the priority given to prevention in clinical practice.

Question 4: *What is the optimal combined strategy for cardiovascular disease prevention?*

This issue is not adversarial and should not pit primary against secondary prevention, or prevention against treatment or rehabilitation. It should be viewed as striving for the best mix of effort, determined by epidemiological and economic principles, and guided by a good dose of prudence and compassion.

The benefits of a collaborative approach should include the recruitment of both the pharmaceutical and the food industry into the partnership. High-risk (drug relevant) and low-risk-population-based strategies are complementary and should be mutually supportive. Additional benefits should include an approach to health care that is more self-reliant (e.g., people taking more responsibility for their own health), and greater recognition for a strong public health approach to disease prevention.

Question 5: *What are the priorities for research in the area of obesity/ overweight as a risk factor?*

I have referred to obesity/overweight at several points in this document, by way of illustration. By and large it is a neglected area of public health research and program development, yet is rife with private enterprise endeavours ranging from the helpful and sound to the frankly exploitative. One of the key issues is to prevent the latter (e.g., inappropriate weight loss is associated with severe psychological disorders such as anorexia nervosa and bulimia). On the other hand overweight is demonstrated to be an important risk factor for hypertension, type II diabetes and hypercholesterolemia, and is at least indirectly associated with adverse cardiovascular morbidity and mortality.

The following constitutes a partial list of topics that deserve attention for research funding in the area of obesity/overweight:

- Further work to establish the role of obesity/overweight as a risk factor in cardiovascular disease, with emphasis on improved methods of measurement and modern research design and analysis.
- The development of a typology of obesity/overweight that is relevant to the potential for cardiovascular disease risks, so as to differentiate types of this condition which are more or less hazardous to the individual. This may require increased collaboration between

Increasing Prevention

- epidemiologists and their clinical and laboratory research counterparts.
 - Further studies of the origins of obesity/overweight in childhood and the longer term influence on prognosis in adult life.
 - Further research into eating disorders (e.g., anorexia nervosa, bulimia) and other possible ill effects of inappropriate dieting/weight loss.
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- The promotion of demonstration projects to evaluate various approaches to weight loss in terms of effectiveness and efficiency, alone or in multifactorial intervention contexts.
 - The promotion of studies, possibly mathematical models, to assess the potential impact of true primary prevention (i.e., prevention of obesity/overweight before it occurs, not after the fact).

RESEARCH PRIORITIES—PREVENTION OF MENTAL ILLNESS AND MENTAL ILL-HEALTH

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No highlights have been prepared for this paper. It is one of a set of papers commissioned separately from the literature reviews to suggest research priorities for prevention.

A number of issues arise when one attempts to identify priorities for research in the mental health field, not the least of which is deciding what it is that we wish to prevent. The answer to this question has great significance, because it has widespread policy and service implications as well as important implications for the conduct of all manner of affairs in Canada.

Another issue is the question of deciding how to assign priority. If we wish to confine ourselves to preventing mental illnesses, as defined by the DSM-III or by the ICD-9, then we need next to address the question of which type of prevention we are contemplating:

- primary prevention, i.e., preventing the initial manifestations of the illness, to reduce the incidence of new cases;
- secondary prevention, i.e., curing the illness once it appears and preventing its recurrence, to reduce its prevalence; and
- tertiary prevention, i.e., preventing or reducing disabilities arising from or as sequelae to an illness, and avoiding deterioration.

With respect to the major mental illnesses, there seems to be a consensus that there are, at present, virtually no effective methods for preventing their occurrence. Because mental illnesses are generally persistent, life-long states, the major burden, both on the individual and on society, comes from the exacerbation of existing mental illnesses, rather than from new cases. Therefore, although research on primary prevention should not be discouraged, at the present time the major thrust in research should be directed toward secondary and tertiary prevention.

Having said this, however, a general statement regarding priorities in primary prevention can be made: that is, that longitudinal research on large groups at high risk of major mental illnesses (e.g., children of persons suffering from major mental illnesses) is needed, to see who develops disorders and who does not. This would assist in identifying causes, mechanisms and factors that underlie the disorders.

AREAS FOR RESEARCH PRIORITY — PREVENTION OF MENTAL ILLNESSES

Work supported recently by the Ontario Mental Health Foundation has assessed the burden of various mental illnesses in Ontario, as classified by DSM-III and measured by statistics such as hospital admissions/separations and average length of stay, and compared this to the amount of money currently being spent on research in the province connected with each of the conditions. By the criterion of "discrepancy" (high burden combined with low research

expenditures), schizophrenia is clearly the condition of highest priority for research.

This study is currently being extended to all of Canada; while it is likely that schizophrenia will top the list of "under-researched" illnesses in all provinces, there may be variations in the ranking of other conditions from province to province. (Researchers wishing further information on these matters should contact the Foundation.)

In addition to research on illnesses identified by the "discrepancy" criterion, research is needed to confirm or explain differential rates of morbidity due to mental illnesses among men and women, as well as to investigate the different use and efficacy of various treatments for specific disorders. The confirmation or denial of sex-related differences in need for, and reactions to treatment may lead to the prevention of misdiagnosis or mistreatment and iatrogenic illness.

Focusing on secondary prevention, particular priorities are attached to:

- the identification of preventive strategies and interventions based on reasonable methodologies;
- longitudinal studies of interventive techniques with children who have high vulnerability (children of parents with psychiatric disorders and children experiencing precipitating factors);
- studies of interventions, over time, with the elderly;
- identification of optimal points for intervention (for example, when the first sign of disorder appears, compared with during the first two years).

Another area which should be considered as a priority for research is the dementias. Advances in preventing death due to injury and infection and the growing number of older people in Canada have contributed to a growing problem: treatment and care for people with loss of cognitive function. This includes both organic types, such as Alzheimer's disease, and induced types, such as brain injury and fever-induced brain damage. Research is needed on preventing the initiation of the dementias and on methods for slowing their progressive advance. Epidemiological research is needed to elucidate the biological bases of the organic types.

AREAS FOR RESEARCH PRIORITY— PREVENTION OF MENTAL ILL-HEALTH

When we broaden our view of prevention to include not just mental illnesses of the DSM-III type to include mental ill-health, then we are looking at

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a whole new field for research and a whole new set of priorities.

First is the area of preventing maladaptive behaviours in children and youth, such as alcohol and drug misuse, delinquent behaviours and suicide.

Second is the prevention of maladaptive behaviours of adults directed towards children and

youth, such as child abuse and exploitation, child sexual abuse, rejection and abandonment by parents, and discrimination on the basis of age or membership in an identifiable minority group.

A third priority area for research is on the mediating effects of social networks on mental health.

ENHANCING COPING

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HIGHLIGHTS

- People face innumerable experiences (e.g., major life events, daily hassles) which are often beyond their control but with which they must nevertheless come to terms. These situations, the resources people use to cope with them and the impact of the resources on their health and lifestyle, are the three components of a simple model of enhancing coping.
 - In general, much of the research done in this field is atheoretical, lacking a clear conceptual basis.
 - While the research to date has provided some knowledge about which coping skills enhance people's ability to cope with particular problems, it has not markedly improved our understanding of why some people, when exposed to certain stressors, exhibit a poor health outcome while others do not.
 - A better understanding of what is involved in enhancing coping and, ultimately, better prediction of public health outcomes may be achieved through multi-faceted measurement of such different processes as subjective self-report, behavioural patterns, and physiological and biochemical function. The added knowledge and understanding warrants the high cost and time required by this approach.
 - Research should focus on:
 - carefully-designed prospective studies, preferably involving experimental manipulation of coping resources, to be conducted by multi-disciplinary teams using a longitudinal approach;
 - low-order, non-experimental studies in areas where experimental approaches may face feasibility or ethical constraints; and
 - productive and highly-specific research in areas related to coping, in order to increase the small body of knowledge which currently exists.
 - Well-designed trials should precede costly, ambitious research projects.
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FRAMEWORK

The schematic framework outlined below has proven to be a useful heuristic tool in categorizing the diverse interdisciplinary literature which was reviewed. The processes envisioned in this framework are consistent with a "web of causation" etio-

logical model, which is gaining increasing popularity within the public health milieu. Although such models are simplistic by comparison with biological, psychological, and social realities, they nonetheless aid in the organization and conceptualization of what might otherwise be an unwieldy body of literature.

STRESSORS	COPING RESOURCES	HEALTH OUTCOMES
Major life events	Intra-personal Personality	Physical illness
Chronic stressors	Coping strategies	Psychopathology
Physical disability	Inter-personal	Quality of life
Psychological	Social support	
Daily hassles	Mutual Aid	

Two facets of working within this type of framework deserve comment. First, recognition of multiple, interacting causal factors in disease etiology makes it possible to accept that a given exposure may or may not be associated with the occurrence of a particular illness. An analogy may make this point clearer: cigarette smokers do not invariably develop lung cancer despite the widespread acceptance of the causal role of cigarette smoking in cancer development. Consequently, this orientation can comfortably incorporate mechanisms which intervene between experiences and health outcomes. Secondly, although the focus of this report is upon "enhancing coping", our orientation in no way tries to "blame the victim" for a particular health outcome or downgrade the role of harmful environmental processes. Rather, our outlook emphasizes that there are innumerable experiences, which are often beyond our ability to control, that we have to come to terms with. How we confront such situations, and their impact upon our health and lifestyle therefore becomes an issue which assumes appreciable significance.

SYNTHESIS OF THE LITERATURE

Stressors

State of knowledge

Major life events examined in our literature review spanned a broad range of experiences including the following: the diagnosis of life-threatening illness, community-level disasters, and job loss. Despite over two decades of research, there is little evidence that such major life events are inevitably associated with poor health outcome. Recognition of this low predictability has had various ramifications. One trend has been a shift towards analysis

of chronic stressors such as crowding or environmental pollutants. Another trend has been to explore the cumulative effect of upsetting daily hassles such as temporary work overload, automobile breakdown, and unexpected company.

Critique

Regardless of whether the frequency or severity of major life events, chronic stressors, or daily hassles is considered, inconsistent relationships between stressors and health outcomes are typically observed. Although appreciable work has been reported, little closure on fundamental issues has been achieved. For instance, instead of performing definitive research that identifies whether a particular manner of quantifying major life events is or is not worthy of further exploration, numerous studies seem to rework the same ground apparently unconcerned with whether the data contribute to understanding. A sound knowledge base seems to be lacking. Proliferation of such unfocused research also tends to encourage one-shot studies that perpetuate narrow analysis of highly specific issues (e.g., intensity of stressful major life events in a conveniently available professional sample). To promote research that continues in such a tradition would seem to be unproductive.

The above approaches have focused on quantification and reported impact of stressors, be they major life events, chronic stressors or daily hassles. A recent, potentially fruitful series of studies has tried to identify common dimensions of stressors such as predictability, controllability, or threat to ego. This strategy is rooted in laboratory work which has demonstrated that the impact of stressors upon well-being is markedly influenced by such dimensions. Finally, an even greater emerging concern is with intervening variables which may moderate the impact of stressors on health outcome.

Coping Resources

State of knowledge

A growing body of literature, spanning approximately 15 years, has tried to identify processes which, by influencing our coping abilities, impact upon health outcome. Two major types of coping resources are recognized: intra-personal and inter-personal. Intra-personal factors refer to personality characteristics or coping strategies which an individual exhibits. Personality factors examined include self-esteem, anger-style, and locus of control. Additional personality constructs such as optimism, coherence, and hardiness have also recently been hypothesized. Coping strategies examined include appraisal, avoidance, information-seeking, wishful thinking, meditation, and physical activity. Inter-personal factors, on the other hand, reflect the influence of others including social support provided by family, friends, or co-workers, as well as more formal mutual aid groups.

Critique

There are several important findings which consistently emerge in reviewing this literature. The following list highlights those points which appear to have greatest significance with respect to efforts to enhance coping.

1. Personality characteristics such as self-esteem appear to influence the degree to which stressors impact upon health outcomes.
2. Temporal parameters may modify the efficacy of coping resources. For example, time since stressor onset has bearing on the appropriateness of a particular resource. Avoidant strategies (e.g., denial, wishful thinking, distraction) which may initially prove beneficial in coping with transient stressors, may ultimately turn out to be counterproductive if persisted in over the long term.
3. Appropriateness of a specific coping resource may be, in part, a function of type of stressor encountered. A strategy such as social support, which is productive in the workplace, may be less effective in dealing with marital discord, where focusing upon intrapersonal coping strategies may be more effective. Alternatively, mutual aid appears to play an important role in certain contexts such as death of a family member, substance abuse, and chronic illness, but may be less effective for dealing with cumulative daily hassles. Moreover, palliative coping strategies which focus on regulating emotions rather than on addressing a modifiable problem-situation may merely whitewash problems and hence, in some settings, worsen them. This element of specificity of coping resources, depending upon stressor characteristics, may have a major bearing on efforts to enhance coping. Thus, indiscriminate efforts to enhance coping which fail to recognize the qualitative aspects of the stressor are unlikely to succeed and, indeed, could prove to be detrimental.
4. Social support of significant others, as opposed to a diffuse network, has consistently emerged as an important coping resource. It ap-

pears that spouse support and a well-functioning family unit may be particularly beneficial.

This list of issues indicates that there have been systematic efforts to identify the parameters associated with efficacy or feasibility of particular coping resources. We have gained some knowledge as to the type of coping resource that might enhance coping with particular problems. In spite of such developments, however, the exploration of these resources has not markedly improved our understanding of why certain individuals exposed to given stressors exhibit a poor health outcome while others do not.

Our review has not included the role which pharmacological approaches (e.g., anxiolytics) might contribute to the question of coping. We do recognize that this question is worthy of inquiry, particularly in moderating the impact of intense, acute stressors, or in controlling chronic psychopathology. However, since this issue is far removed from our areas of expertise, we chose not to address it.

Health Outcomes

State of knowledge

Health outcomes examined have included depression, anxiety, physical symptoms, major illnesses, and quality of life. Mortality and the time from diagnosis to death have also served as outcome measures. In addition, there has been a trend to examine minor infectious illnesses and more objective measures of health, such as immune function. Neuroendocrine responses and other processes implicated in disease have also been examined.

Critique

In this domain, there has been less ambiguity as to what should be measured, but greater difficulty in obtaining objective measures, particularly in the case of psychological outcomes. In the vast majority of the literature, unsubstantiated self-report of symptomatology is the norm. A notable exception comes from the pediatric literature in which a child's self-report is often corroborated by independent reports from family, teachers, and hospital staff (e.g., Drotar & Crawford, 1985). Work examining the impact of coping on neuroendocrine and physiological responses implicated in disease (e.g., Frankenhauser, 1986) has often stopped short of extending these investigations to follow up whether disease actually occurs. A recent appeal (i.e., Fleming & Baum, 1987) for multidimensional measurement (i.e., self-report, objective, physiological) seems both timely and apt.

GAPS IN KNOWLEDGE

First, systematic research which seeks to gain closure on fundamental issues is rare. Although we have bits of understanding regarding highly specific pieces of the

puzzle, how or whether these fragments fit together into a meaningful picture is unclear. Although numerous models of coping have been proposed, incisive research which critically tests these models is scarce. Much of the research is atheoretical, lacking a clear conceptual basis.

Second, powerful prospective and experimental designs are rarely seen. Studies are typically retrospective and correlational. When intervention studies are reported, subjects have normally selected which treatment program was received. Drawing sound inferences from such designs is difficult. Although prospective studies are becoming more common, they often rely on statistical techniques rather than experimental manipulation to infer causality.

A truly preventive approach might involve developmental studies which track, from early childhood, certain personality traits (e.g., withdrawal from social interactions). A prospective design permits assessment of the stability of social behaviour in childhood and adolescence with the goal of predicting later psychopathology and adjustment. A group which is currently being identified as at-risk for pathology is that of aggressive and withdrawn pre-adolescents, particularly females (Schwartzman, Ledingham, & Serbin, 1985). It should be noted that once risk factors are identified in a prospective design, an experimental approach may be used (in tandem, using a cohort design) to evaluate the impact of interventions. For example, using a cohort procedure, the suggested importance of factors associated with psychopathology in an older group may indicate the need to evaluate intervention efforts in a younger group (e.g., Bell, 1953). Undoubtedly, there are ethical issues involved in such protocols with regard to the appropriateness of trying to intervene to alter personality patterns, but if a clear pathogenic link can be established, such issues may have to be confronted more frankly.

Third, little attention has been directed towards the study of process measures which could identify mechanisms through which coping resources have bearing upon health outcome. For example, does social support from a spouse act intra-personally by bolstering a personality characteristic such as self-esteem or by promoting use of an alternate coping strategy such as reappraisal of the situation? Identification of such process variables would have clear implications for the development and assessment of interventions to enhance coping.

Fourth, there is insufficient research directed to improving the quality of life for target groups such as the chronically ill, the bereaved, and the unemployed. Since such groups may be predisposed to exhibit negative health outcomes or even suicide, they may be able to uniquely benefit from relatively inexpensive interventions such as mutual aid.

METHODOLOGICAL CONSIDERATIONS

While the principal criticisms of the work reviewed are related to conceptual and design issues, there are certain methodological aspects which need to be considered. These apply equally to the three elements of the framework. Reliability is the bare minimum prerequisite for any measure, and in the majority of cases, was found to be acceptable. The question of validity is, however, less clear. This may simply relate to the state-of-the-art in assessing variables which are difficult to quantify. For example, the assessment of personality through self-report instruments which have been validated using clinical populations may present problems when used with non-clinical groups. Moreover, although certain measures may appear on the surface to be measuring important processes, this may not be the case empirically. Finally, the positing of novel personality constructs (e.g., optimism, coherence) may simply be a case of measuring the same thing given the strong correlations which exist between these supposedly discrete concepts.

A critical issue relates to the use of self-report measures. Since subjects may often tell experimenters what they think the experimenters want to hear, controlling for such expectancy effects, particularly in the coping area, may not be a trivial matter (Friedman, 1980). Objective measures (third party corroboration, behavioural and physiological indices) have been used to try to circumvent such difficulties and their continued use should be encouraged.

SUGGESTED INDICATORS

Two suggestions regarding indicators emerge from our evaluation of the literature and discussions with colleagues. First, an issue that is independently being raised by researchers from varied scientific perspectives in different countries is the need for multifaceted process measurement (Fleming & Baum, 1987; Payne & Jones, 1987). To better understand what is involved in enhancing coping, it may be necessary to concurrently monitor processes at quite different levels: subjective self-report, behavioural patterns, physiological and biochemical function. To implement such complex measurement protocols, particularly in a longitudinal context, can involve appreciable expenditure of time and money. However, it is precisely this type of research which may allow us to gain a clearer understanding of the multifaceted aspects of coping, and ultimately allow us to better predict health outcomes.

Second, there are instances, particularly with high risk populations, where process and outcome measures can be monitored concurrently in a longi-

tudinal design. We found one thoughtful and well-designed instance (Franklin et al., 1987) in which quality of life and efforts to enhance coping in recently released mental patients was monitored in a setting in which actual utilization of the health care system could be accurately quantified. Although issues of confidentiality have to be addressed, it is possible, through a blind coding system, for researchers to be able to access data in such situations without identifying individual patients. It is rare to see such well-conceived and carefully conducted research. The findings of this study are discussed later under political and social considerations.

NEEDS FOR DATA

While our review suggests the need to tailor the resource to the stressor, in some instances, the utilization of coping resources which are not directly relevant to the stressor may be indicated. Typically, efforts to enhance coping emphasize the introduction of new resources (e.g., social support, physical exercise) rather than exploiting existing resources (e.g., hobbies, favourite activities). Although specific problem areas need not be targeted, impressive generalized behavioural changes can be observed. An example of this type of approach may make the point clearer. Behavioural problems in primary school children were greatly ameliorated by having parents monitor and take greater interest in their children's homework (Patterson, 1986).

A critical issue to address is that regarding the modifiability of coping resources, which can occur at intra-personal and inter-personal levels. Related points are discussed below.

a) *Intra-personal*

It is often the case that individual coping strategies which successfully predict outcome no longer do so when stable personality traits are co-varied out. In such cases, the personality trait itself may prompt selection and utilization of particular coping strategies. For example, optimistic individuals are more likely than pessimistic individuals to use problem-solving approaches as opposed to avoidance strategies. The latter includes focusing on the emotions engendered by the problem rather than on the problem itself. Since it is generally accepted that modification of stable personality traits such as optimism is unrealistic, it may be preferable, in terms of time and expense, to teach people specific coping strategies that optimistic people employ. For example, in the case of examination stress, progress towards studying would be optimized by a strategy characterized by the suppression of competing thoughts and distractions. This suggests that it would generally be more expedient

to intervene by changing an individual's coping strategies than to attempt to alter personality. It is important to note that the above rationale implies that the superior health outcomes evidenced by optimists are in fact due to the use of these strategies, and not to other variables simply associated with having an optimistic outlook. This possibility could be tested by the sampling of a host of such variables and statistically demonstrating that their association with health outcome is not significant.

b) *Inter-personal*

Another example of modifiability and realistic intervention targets concerns the inter- versus intra-personal domains. There are indications that in many job situations it is ineffective to intervene on an individual level. Thus, trying to get an individual to cope with unrealistic job demands is less fruitful than intervening on a group level, either to reduce distress through sharing difficulties or achieving consensus towards attacking the source of stress. Similarly, broader forms of intervention could effectively be implemented at the organizational or community level. A related issue is the question of the modifiability of support by a significant other or family members, which our review suggests is often of vital importance.

Finally, there is need for more comprehensive measurement of utilization of coping resources, health outcome and quality of life using self-report, behavioural and physiological measures that triangulate on the phenomena in question (e.g., Payne & Jones, 1987). Such an approach provides a multi- rather than uni-dimensional perspective regarding the resource or outcome under investigation.

PRIORITY QUESTIONS FOR RESEARCH

Three priority questions for research are identified. Our principal recommendation is that carefully designed prospective studies, preferably involving experimental manipulation of coping resources, are required. Since such work will necessitate repeated monitoring of the three principal factors in the working framework (i.e., stressors, coping resources, and health outcomes), an interdisciplinary team with relatively substantial long-term funding may be best suited for this task. This approach would seem to be essential if we are to identify which coping resources best permit particular stressors to be experienced with least health risk. Such longitudinal designs might also aid in identifying whether optimal coping resources may change as a function of the time since stressor onset. The proposed approach may also allow the identification of certain stressor-resource combinations which are associated with positive health out-

comes. A "decision tree" may be thus created, in which prescriptions for enhancing coping may be more confidently proposed.

Secondly, while emphasizing the need for comprehensive inquiry, we also recognize that in some cases, lower-order non-experimental research may still be justified. For example, certain personality characteristics that appear to influence coping may be relatively robust and resistant to change. In such circumstances where experimental manipulation may not be feasible, or where there may be ethical constraints, it may still be necessary to assemble data from which to generate hypotheses and conduct sound analytical studies. An example of this latter approach is the utilization of elaborate statistical techniques such as path analysis to explore how personality patterns influence coping (Wheaton, 1985). Moreover, with naturally-occurring coping patterns, such statistical approaches may provide a basis for later experimental interventions.

Third, the identification and nurturing of pockets of productive research, even though the work may not immediately lead to health interventions, would seem to be a prudent measure. Our literature critique unearthed little high-quality research and consequently, the extent of accumulated knowledge was not overwhelming. Clearly, if rigorous criteria (Sackett et al., 1985) were employed, little of the literature reviewed could pass through the sieve. Nevertheless, our scrutiny of the literature did reveal that there are a few individual or groups of researchers who have worked carefully and thoughtfully on problems related to coping. This is often reflected in a systematic progression from descriptive or correlational research to more prospective or manipulative designs. Although these researchers may not be at the stage where they can firmly advocate the implementation of clinical trials, they are nonetheless making headway towards improving our understanding of coping. Since support of such individuals or teams may not fall under the current rubric of the National Health Research and Development Program, the underwriting of such research efforts might be an area where the Health Promotion Directorate could have unique impact.

POLITICAL AND SOCIAL CONSIDERATIONS

We supplemented our critique of the literature by consulting colleagues in applied and public health settings. In general, the consensus view is that there is at present insufficient evidence for confidently proposing political and social action. There are, however, certain cases where cautious implementation of specific interventions may be indicated. One of these derives from laboratory work demonstrating the deleterious impact of uncontrollable and repetitive work situations (Frankenhauser, 1986). This carries implications for structuring the working environment to allow for latitude in decision-making, as well as varying the nature of the work so as to minimize monotony and boredom. Another case is related to the promotion of mutual aid groups for target populations at risk for poor health outcomes (e.g., the bereaved).

However, for the most part, we caution against intervening prematurely with costly, ambitious projects before conducting adequate well-designed trials. An excellent example of a prematurely launched program is the introduction of case-management for the chronic mentally ill throughout the United States (Franklin et al., 1987). Under case-management, a health care worker assumes responsibility for linking a client, just released from an in-patient facility, with a wide range of services (e.g., rehabilitation, mutual aid, emergency care). A recent manipulative study revealed that case-management, in contrast to simple access to the services already provided in a community, resulted in *increased* hospital admissions, *greater* use of community-based services, and *lower* quality of life. Thus, the attempt to coordinate resources resulted in greater costs to the community coupled with poorer outcome. Was the implementation of such a costly and ineffective intervention really warranted? Well-designed field studies on small, representative samples might have yielded data sufficiently compelling to identify the shortcomings of an intuitively appealing, but empirically ineffective program. Perhaps we can learn vicariously from our neighbour's mistakes.

4. THE MECHANISMS

Achieving Health For All identifies three mechanisms which it describes as being intrinsic to health promotion. They are

- self-care
- mutual aid
- healthy environments

People acting in ways that protect or improve their health, people coming together to offer each other support in mutually-reinforcing ways, and people moving to alter the social or physical environments in ways that are conducive to health, are all using these mechanisms to contribute to the promotion of health.

None of the mechanisms is clearly defined. *Mutual aid*, for example, is far from being a scientific term and the papers in this section illustrate that what it includes and what it excludes are still very much a matter of debate. Mutual aid relates to the functioning of informal caregiving networks. Such networks are increasingly being seen as important in protecting and improving people's health, acting as a buffer to stress, and perhaps even increasing resistance to disease, but the research effort has only just begun.

Joy Rogers of the Clarke Institute of Psychiatry in Toronto suggests that the recent proliferation of mutual aid/self help programs may be both a public response to unmet social and health needs and a professional response to research into the role of social support in protecting health and preventing illness. She warns against two dangers: that of co-opting informal helping/mutual aid strategies as adjunct services under professional control, and that of viewing the mutual aid approach as "a cheaper substitute for health and social services." John Esdaile and his colleague from the Montreal General Hospital's Department of Medicine explore the relationship between social support and health in patients with arthritic or rheumatic disease, the third most common cause of activity limitation in Canada.

By far the largest proportion of health care given in Canada is *self-care*—some estimates put the figure as high as 95 per cent. This makes it crucial to understand the nature and scope of self-care, the circumstances which promote it, and its true potential as a health-promoting mechanism. People need to be supported in their efforts to protect their health and that of their families, to handle minor illnesses, and to manage chronic conditions. Robert Perrault of the Clinical Research

Institute of Montreal considers that the aim of self-care should be to develop a more efficient health care system, one based on a fuller exploitation of "every component and every competence," and on the dynamic and integral involvement of people in their own health care. The literature reviewed in Perrault's paper suggests that there is much research to be done in this area, which, among other things, offers rich possibilities for "high-tech" applications. The literature also shows how self-care is alternatively viewed as an empowerment strategy and a cost-containment strategy.

We are only just beginning to understand the immense impact that our circumstances and our surroundings as opposed to our lifestyle can have on our health. Exploration of the mechanism of *creating healthy environments* is limited only by the imagination. The environment is the community, the family, the workplace; it is the air we breathe and the water we drink; it is the system of laws that govern us; it is the buildings we live in and the social policies that shape our society; it is the safety of our streets, the quality of our transportation system and the accessibility of recreation. Environment is the business of the legislator, the urban planner, the policy-maker, the chemist, the engineer and the educator. And every citizen has a right and an obligation to work and to press for changes that will make the environment healthier. Achieving Health For All points out that environmental change is by far the most complex and the most difficult of the three health promotion mechanisms. Bruce Small and his colleagues urge that our extensive knowledge of the impacts of social and physical environments on health be applied to the design of health and other social programs, as well as the design of physical settings.

What is the relationship between self-care, mutual aid and public participation? Does self-care occur before self-help? And are they both prerequisites to public participation? And what public is it that engages in self-care and self-help? Is it reasonable to speak of self-help and health inequities at the same time? Will the creation of healthy environments reduce inequities, opening the way to self-care?

The questions are legion and the linkages among the three mechanisms as well as between them and other framework elements need to be explored. In her paper, Rogers speaks of social support as "a crucial environmental coping resource," thus showing that the mutual aid mechanism, the challenge

of enhancing coping and the mechanism of creating healthy environments are all related. Clearly, there is much research to be done before we can

work out "ideal" combinations of mechanisms and strategies to meet particular types of challenge.

SELF-CARE: A REVIEW OF THE LITERATURE

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HIGHLIGHTS

- The term "self-care" refers to decisions and actions initiated and controlled by individuals and/or their families, for the purpose of promoting and protecting health, curing minor illnesses, or managing chronic conditions. Self-care has been viewed both as an empowerment strategy and as a cost-containment strategy.
 - Self-care is not a substitute for available health care resources, nor does it eliminate the need to modify socio-environmental conditions that are detrimental to health. Rather, the aim of self-care should be to develop a more efficient health-care system, one based on fuller exploitation of every component and every competence, and on the dynamic and integral involvement of people.
 - Promoting self-care means ensuring that people are equipped with appropriate health information and management skills, so that:
 - they make appropriate decisions regarding action on new symptoms
 - adequate treatment is available for minor symptoms
 - good self-management of chronic diseases is possible
 - optimal compliance with prescribed treatments is achieved
 - unhealthful habits are modified
 - people recognize and act on unhealthy environmental conditions
 - The evaluation literature looks at *medical self-care* (decisions and actions concerning new symptoms) and *general self-care* (these aimed at managing and controlling previously-diagnosed conditions). Taken as a whole, it makes conclusions impossible on whether self-care programs have a positive impact on health behaviour or health status, or even on whether one approach has any merits over the other.
 - Studies suggest that mediating psychological factors, such as health beliefs, self-efficacy and health locus of control may be directly or indirectly related to health behaviour.
 - Areas for investigation include:
 - the decision-making process (identification and assessment of health problems, optimal conditions for decision-making, etc.)
 - self-care technology (computer-assisted self-care, home-testing, over-the-counter drugs, books and pamphlets and integrated self-care programs).
 - A multidisciplinary approach to the study of self-care is needed, using qualitative methods. Research on the phenomenon itself should be guided by descriptive methods from fields such as epidemiology, sociology and psychology. Research on self-care as an intervention should draw on fields such as health communication, computer science and cognitive psychology.
 - A consensus conference on self-care would help to define the field and clarify its objectives, and assist researchers to design useful and generalizable studies. Self-care research guidelines would help to generate funding.
 - Priority must be given to research in the following areas:
 - describing self-care behaviour
 - promoting self-care to various target groups
 - developing self-care decision-support systems and training programs, using computers as a central strategy
 - undertaking prospective community-based trials using integrated self-care programs
 - Demonstration and development projects are needed, and models of self-care programs and technologies must be piloted.
 - In particular, the following should be established:
 - storefront self-care resource centres, as clearing-houses for self-care literature and material
 - a computer network for self-care
 - a self-care task force.
-

INTRODUCTION

Self-care is the oldest form of health care. The term refers to the decisions and actions initiated and controlled by the individual and/or his or her family. The goals of self-care are the promotion and protection of health, the cure of minor illnesses, and the management of chronic conditions.

This review looks at the nature of self-care, the decision-making process involved, as well as the implications for research and policy development.

SYNTHESIS OF THE LITERATURE REVIEW

The nature of self-care

While self-care has always been a part of the role of the family, it has acquired a new visibility in most industrialized countries. This interest is shared by public officials, health professionals and consumers alike. Among the factors most often invoked to explain it are the aging of the population, the high prevalence of chronic conditions, the apparent limitations of technological medicine (i.e., its failure to impact on socio-environmental factors responsible for many health problems; its iatrogenic potential; its bureaucratic structure; the inequality of resource distribution and accessibility; and its problems with cost containment), as well as the emergence of a strong consumerist approach to health in the population, with an emphasis on autonomy.

Studies show that self-care presently plays a central role in health-related decision-making and behaviour. Formal medical resources, in fact, represent only the tip of the iceberg.

Decision making

Mainly in relation to minor ailments, but quite frequently for symptoms that precede a major illness, people often choose not to act, or, more specifically, to monitor the evolution of their problem. When a decision to act is taken, it is more often than not a decision for self-treatment. In fact, studies suggest that medical self-care is chosen as 85 to 95 percent of all medical care. Different symptoms are differently treated, and agreement is low between individuals, between professionals, and between these two groups, as to what constitutes a proper self-care indication.

The decision to call a physician, to self-treat or to do both is influenced by many factors. Studies looking at this process are not consistent and suffer from too much methodological variation to permit generalizable conclusions. Nevertheless, a number of factors emerge: 1) nature of the problem (as well as severity, duration and number of symptoms); 2) socio-demographic variables; 3) in-

dividual profile (disease-related anxiety, health beliefs, locus of control, perceived self-efficacy, etc); 4) objective obstacles to consultation (transportation, physical mobility, work constraints, etc); 5) characteristics of previous contacts with health professionals.

What seems clear is that the factors determining the choice of medical consultation are the same as those determining self-care. It is therefore difficult to see these behaviors as antagonistic.

Self-care technology

The market offers a number of tools to support self-care. Many lists and catalogs make attempts at classifying them. The present review is augmented by a small survey conducted in the form of a simulation of four user perspectives, as represented by an experienced television researcher looking for information. Its objective is to test availability and access to self-care materials in a large urban area (see appendix of the full report).^{*} It concludes that although some material is available, it is impossible at present for consumers to make sense of what is available. Quality varies, and source credibility is also quite heterogeneous. Although health care services do offer health education mainly for chronic conditions, very little is available to support self-care approaches to lifestyle change and to support decision-making. No comprehensive self-care oriented programs were found.

Over-the-counter (OTC) drugs are an important part of the self-care environment. Their omnipresence and their number suggests the need for good studies dealing with their use.

Home testing is a new and rapidly developing field in serious need of evaluation. While providing powerful ways to diagnose or monitor certain conditions, validity of results as well as the training necessary for interpreting them are in question.

Many authors stress the importance of evaluating home medical tests. Product specifications, test sensitivity, specificity and "user-friendliness" are among the aspects to be evaluated.

Educational tools are also part of the self-care paraphernalia. They traditionally take the form of pamphlets, "how-to" books and medical encyclopedias.

Pamphlets are usually produced by volunteer associations and government agencies. They are rarely evaluated and seldom updated. Books are produced by individuals who may or may not be qualified. Content validation is therefore essential. In order to do this, some authors suggest adequacy criteria. Few studies have attempted such validations.

^{*} For information on how to obtain the full report, see page 8.

Computer applications in self-care and health education are now being studied. While most applications deal with health education, decision support systems have recently been designated and validated.

Numerous education programs for microcomputers have been produced. Some have been shown to be quite useful but the quality of most has not been evaluated, in part because of their recent development. The literature agrees on some of their advantages:

- tailoring of information according to needs;
- standardization and easy updating;
- adaptation to individual learning styles and pace;
- participation and interactivity;
- easy repetition;
- immediate feedback;
- constant accessibility; and
- total user control, etc.

It must be noted that many of these characteristics match Green's criteria for efficient person-to-person health education. Drawbacks identified are mainly related to "newness" of the technology: set-up costs; few sophisticated programs; worries about dehumanization. There is general agreement about the promises offered by computerized approaches to self-care and health education.

Evaluation

Many health education and decision support programs have been evaluated, using varied tools. These programs may be grouped in two broad categories: Category 1, medical self-care, deals with decisions and actions about new symptoms; Category 2, general self-care, deals with decisions and actions aimed at managing and controlling previously diagnosed conditions.

Medical self-care evaluations look at variables such as reductions in the number of "trivial" medical visits and augmentation in the number of "necessary" consultations. To achieve such objectives, some randomized, controlled trials have used self-care programs built around algorithm-based, structured self-care manuals. Results have been promising in terms of reduction, but no clear documentation of a rise in "appropriate" visits was made. This effect was accompanied by higher self-efficacy scores.

Other studies have looked at telephone consultation with non-professionals or using taped messages. They show that non-professionals provide adequate services. No study has compared professionals and non-professionals using the same approach.

General self-care studies dealing with management of chronic conditions use heterogeneous methodologies, target groups and designs. Results are difficult to compare, and generalizations almost impossible. It is even difficult to sort them according to intervention types.

These studies look at measures of impact on knowledge, skills, health behaviour and health status. The great majority of programs show an increase in short-term knowledge, but little long-term retention. Behavioural impacts are not clear. Some studies do show knowledge and skill acquisition, as well as daily application of the skills, but others fail to do so. The same mixed results are to be found when health status is considered.

An interesting aspect of this literature lies in the fact that the studies shed light on the influence of mediating psychological factors, such as health beliefs, self-efficacy and health locus of control. Such factors could exert either a direct influence (in that their improvement brings about an improvement in the health status), or an indirect influence (in that their improvement brings about positive changes on health behaviours, which, in turn, influence health status).

As a whole, this literature does not allow any conclusions to be drawn on whether these programs have a generally positive impact on health behaviour or health status; conclusions are even less possible with regard to the merits of one approach over another.

Compliance as a self-care issue

Compliance with treatment has, in recent years, become a field of intense scientific activity. Many of the determinants of compliance may be related to self-care. Among those related to patients, one finds such variables as social isolation, self-image, self-efficacy, etc. One educational model links non-compliance with lack of knowledge about the disease and its treatment; a more complex version deals with the patient's beliefs about the illness and his or her own vulnerability. Disease and treatment characteristics (such as severity, duration, interference with daily routine) are also known to influence compliance. Finally, the quality of the relationship between the professional and the patient is often invoked. As can be seen, many of these factors are components of the self-care paradigm.

The behavioural methods as well as the more specific educational approaches applied to the problem are all aimed at providing patients with better control over treatment variables through facilitation of the decision-making process. These attempts at empowering patients to become active participants in their treatment may at times result in more non-compliance, with patients making their own decisions about treatment variables such

as side effects. Information is therefore identified as a fundamental tool.

Another piece of data may be of interest to research and to treatment of non-compliance: a few studies have shown that compliance may have a positive effect that is independent of treatment. Improvements in health status have been observed repeatedly in patients who are compliant with placebos.

Lifestyle and self-care

The few self-care-based lifestyle change programs included in the present review use high-quality methodologies. They identify good predictors of success or failure in changing habits such as smoking. Once more, self-efficacy seems to emerge as a central factor. One study, comparing various tools to support self-change, points to the importance of a self-care manual for maintenance of positive changes.

IDENTIFICATION OF GAPS IN KNOWLEDGE

This review suggests a number of gaps in the knowledge on self-care. The first problems deal with how self-care is defined. Terms like medical self-care, self-help and general self-care are being circumscribed but little is known about cultural variations applying to such definitions.

Decision-making

Self-care behaviour has just started to be studied. Health-problem-solving, network-building and natural decision-making processes have been looked at in a few studies, but not in enough depth. There is a need for work on how people identify and assess health problems. Information on how cultural and cognitive variables influence such processes is also needed.

Other areas of study should cover optimal conditions for decision-making, e.g., access to information, meta-cognitive processes as they relate to self-care training, and reinforcing and dissuading factors.

Technology

The tools of self-care have been found to be numerous if a bit anarchic in both format and organization. In most cases, studies looking at self-care technology are not yet matching the potential suggested by this area. A few cases in point

• Computers

Using computers as support systems for self-care training and decision-making is a recent development. This is understandable in the light of the evolution of computer science and technology. Only recently has the study of human factors made

possible the "user-friendly" interface with computers that is essential to their utilization by "naïve" users. The same can be said of fourth generation programming and content development. Good education and decision-making programs have been developed. There is a need to support this field of research. As well, studies must now be undertaken on the behavioural and health impacts of computer-assisted self-care. At another level, little is known about the implementation strategies for such systems, their cost-effectiveness or their integration with the health care system.

• Tests

Biological testing can now be conducted by lay people in their homes. This new field has become a "market" before anything is really known about it. Home-testing has the potential to reduce costs, clutter and dependency on the health care system. It also has the potential to help individuals take control of their health by providing monitoring instruments. Because of high need and profit potential, home tests have been launched on the market without enough quality control and with very little utilization data. No body of studies exists relative to their validity and sensitivity when used by untrained people. No standards have been developed to guarantee ease of use, nor have there been enough studies looking at the impact of such tests on the health care system, particularly on the patient-physician relationship and on physician behaviour.

• OTC drugs

Over-the-counter (OTC) drugs have been around for a long time. Their number is impressive and it is difficult for the consumer to know much more about them than is advertised. As a major, if not THE major, self-care technology, OTC drugs need to be studied more intensively in terms of effectiveness and utilization patterns.

Furthermore, little is known about how people can be trained to use them systematically as part of a planned treatment comprising self-evaluation and consultation decisions if needed.

• Self-help books and pamphlets

The uses and limitations of self-help literature have been fairly well documented. It is clear that not enough evaluation of such materials is ever undertaken. One conclusion emerges from this literature: printed materials are more useful to self-care when integrated with a "program" of some sort.

• Integrated self-care programs

The patchwork approach to self-care is often deployed, making evaluation difficult. It is probably a sign of burgeoning maturity that a few prospective, controlled trials of integrated self-care programs are emerging. Sadly, it is also a sign of the low visi-

bility of self-care at the granting agency level that so few have been conducted.

There is a great need for studies that put the most promising self-care technologies to use in programs that are integrated to specific health care systems. Only such large-scale studies will be able to provide data that can influence future policy.

In all these areas, from decision-making to integrated programs, good progress has been made and promising results are appearing. It is nevertheless clear that a great many questions are still unanswered.

METHODOLOGICAL CONSIDERATIONS

The uncertain impact of health education and health promotion programs on health behaviour and health status suggests that outcome evaluation alone may not yield sufficient information. It is possible that many mediating variables may have been overlooked. As well, full functional analysis of the problems of responsible lay decision-making in health has yet to be perfected.

Looking at the field, one gets the impression that it has been developing on methods and concepts borrowed from disciplines such as epidemiology, clinical medicine, sociology, anthropology and behavioural science. It may also have evolved as an extension of professional intervention with a look toward quick results. Now, it is imposing itself as a full-fledged discipline, mainly as a result of the coming together of many interests. Some proponents are interested in self-care as an empowerment strategy for gaining autonomy in health management. Others see it as a cost containment strategy. Whatever the ideologies supporting self-care, it is time to request resources, so that, from a research perspective, it may receive the full attention of a multi-disciplinary group of investigators.

Qualitative methods should be applied to analyzing self-care behaviour, from problem identification, to the search for alternatives, to implementation and follow-up of interventions. From this data should come better targeted and better adapted tools and interventions. Funds should also be allocated to perfecting more sophisticated self-care technology flexible enough to adapt to the fact that health is not always at the forefront of people's minds.

From such work, it will then be possible to develop indicators and interventions that can be tested in prospective controlled trials.

Two perspectives may be used to guide research. Self-care as a phenomenon commands good descriptive methods from fields such as epidemiology, sociology and psychology. Self-care as an intervention commands research from fields such

as health communication, computer science and cognitive psychology.

A useful way to give self-care research a unifying boost would be to call a *consensus conference* on the subject. This would not only serve the purpose of helping investigators to design useful and generalizable research but, by delineating the field more clearly, help self-care to become a "fundable" topic. Clear definitions and objectives have in the past helped to open up funding for other disciplines. Self-care research guidelines should be a central part of the effort to generate health promotion research funding.

SUGGESTED INDICATORS

The present state of knowledge suggests a number of indicators by which self-care may be looked at.

Anxiety, problem solving skills, health locus of control and self-efficacy are among the intermediate variables found to be sensitive to self-care interventions. Each indicator is, of course, part of a large body of research that will not be discussed here. The fact that these indicators are psychological in nature, and mainly based in social learning theory, underlines the usefulness of this paradigm in understanding and measuring specific human behaviours. It also reflects the lack of studies of self-care by other fields. Although this observation may be due to a selection bias attributable to the present reviewers, it is only partly so. References to other paradigms found in the literature all tend to support this view.

Impact variables, such as self-care behaviours (skills), health status, health services utilization, efficiency and health services organization, are mentioned in the literature. Of these, attention should be given to refining health behaviours and health services organization indicators. It is felt that because of the early stage of research on self-care, priority should be given to behavioural indicators. Progress in improving behavioural indicators is necessary before health status and economic indicators can be considered.

DATA NEEDS

Data are needed on spontaneous self-care practices, networking, lay consultation behaviours, information-gathering, validation and utilization in order to define "baseline" self-care behaviour. As well, cross-cultural data are important in order to understand the varied interpretations and meanings given to self-care.

Clarification of how professionals, health administrators, politicians and consumer advocates view

self-care is also in order, and surveys should be conducted in this regard.

It is important to characterize the determinants, and the facilitating, maintaining and reinforcing factors of self-care. Needs must be listed by priority. Scientific information must be translated into usable formats.

PRIORITY QUESTIONS FOR RESEARCH

From the above considerations, the following research priorities are suggested

1. Description of self-care behaviour.
2. Studies on the promotion of self-care to various target groups (i.e., the general public, the chronically ill, surgery patients, etc.).
3. Development of self-care decision-support systems and training programs, using computers as a central strategy.
4. Prospective community-based trials using integrated self-care programs, in order to look at behavioural impacts on users and professional as well as economic and health care organization impact.

POLITICAL AND SOCIAL CONSIDERATIONS

Creating a self-care interface between the general public and the health care system obviously presents many advantages. For the consumer, it is a natural and familiar way to deal with health issues and problems. For health professionals, self-care represents—thanks to information technology and health communication—a real possibility to make scientific knowledge available in forms that were previously impossible. This can be done without compromising tested practices or status. For the policy-makers, the self-care interface might contribute to cost containment by helping to bring the demand for health care services into better balance with the supply.

Nevertheless, implementing any formal self-care policy raises a number of potential risks. Self-care should not serve as an excuse to reduce the variety and quantity of health care resources available, justify inequality in access or distribution of resources, nor should it be used as an excuse not to work on modifying socio-environmental conditions that are detrimental to health.

Health care and self-care are not opposites. They are, by necessity, complementary. There is no point in looking at self-care as a means of reducing demand for services. More specific utilization should be the goal: an increase in the number of timely consultations, and a decline in the number of trivial consultations. The latter are known to use

up considerable resources and to reduce satisfaction on the part of professionals. In order to achieve this improved balance, the public's role in health management must become more dynamic. Such participation implies having better access to information, in forms and at times whereby it will contribute to raising competence for self-care.

The present movement in favour of self-care offers possibilities and challenges to traditional health care services. Failure to see these possibilities or to take up these challenges will surely contribute to lowering the quality of health care services in an era of financial constraint. Taking up the self-care challenge may very well contribute to the development of a more efficient health care system based on fuller exploitation of every component and every competence. With the aging of the population, it is high time to treat people as an integral, dynamic part of the health care system.

IMPLICATIONS FOR ACTION

Promoting self-care is making sure that

- appropriate decisions are made relative to actions to be taken in presence of new symptoms;
- adequate self-treatment is implemented for minor problems;
- good self-management of chronic diseases is possible;
- optimal compliance with prescribed treatments is achieved;
- unhealthful habits are modified.

Promoting self-care also means helping people to develop the necessary skills to recognize and take action to modify those social and environmental conditions that are responsible for generating disease or unhealthful behaviour.

In order to achieve any of these goals, individuals need to become better equipped: health information and health-management skills become essential. If active public participation is to be favoured, society must make sure that decisions and behavioural choices are optimized. Access to comprehensible information that is easily applied must become a priority.

Research alone will not drive the creation of the self-care interface. Demonstration and development projects are needed. Models of self-care programs and technologies must be piloted in order to initiate an iterative process that will give life to this new reality. Some suggestions

1. Storefront self-care resource centres

These centres would serve as a clearing-houses for self-care literature and material currently available on the market. The field study conducted for

the present review suggests that the haphazard distribution of such materials as well as the "fuzzy" role of health services as distributors contribute to the lack of direction in the use of self-care. The self-care centres could be part of a field study of self-care. It must be stressed that materials do exist presently, but they do not get to consumers in a coherent fashion.

2. Computer network for self-care

The difficulty of gaining access to appropriate information to support self-care decision-making has been stressed. It is suggested that a network of computerized self-care stations be implemented in selected areas, as part of a wider self-care program that would also include a promotional component and liaison with health care services. This network could reach people in environments similar to those where there are automatic banking tellers, or be made available in the home. It could be linked to central computers, or offered on "stand-alone"

microcomputers. The content material for such a network has already been developed in Canada and, on a more limited basis, in the United States.

3. Self-care task force

A small task force, composed of experts and representatives of the community interested in self-care, should be put in charge of designing a number of field experiments aimed at developing a self-care interface. The task force would consider the various options and objectives to be pursued and, in collaboration with researchers, suggest specific packages to be tested in various environments.

This approach is, of course, more directive than traditional grant agency funding. It offers a number of advantages for a field of study that has had a long tradition of directionless research and borrowed methods as an extension to other areas of research. The task force could set three-year timeframes for its action.

SOCIAL SUPPORT AND SOCIAL NETWORKS AS PROMOTERS OF PHYSICAL AND PSYCHOLOGICAL WELL-BEING IN PERSONS WITH ARTHRITIC AND RHEUMATIC DISORDERS*

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* Summary version

HIGHLIGHTS

- There is a growing recognition among researchers that psychosocial and economic factors play a role in the causation, prognosis and treatment of arthritis and rheumatism. This has led to renewed interest in the role of social support in promoting both physical and psychological well-being in individuals with these diseases.
 - Social support is broadly interpreted as encompassing socio-emotional and/or instrumental aid provided to an individual by persons in his/her informal *and* institutional networks. Thus understood, social support may be given by family, friends, neighbours and co-workers, as well as by health professionals, ministers, teachers, social workers and counsellors, and would include such things as old age and disability pensions, provision of public schooling, etc.
 - While the literature provides little evidence that social support is a risk factor in arthritic and rheumatic diseases, it does indicate that low educational attainment is strongly predictive of risk of these diseases.
 - Moreover, perceived family support is a consistent predictor of positive social outcomes in arthritic patients. However, the findings are inconsistent on the role of social support as a predictor either of compliance with prescribed treatment or of clinical status in such patients.
 - An individual's susceptibility to the consequences of arthritic disease is related to his or level of educational attainment; persons with more education are better able to cope with the disease. Social predictors of work disability for arthritic persons include education, family income and job characteristics.
 - The literature review reveals the need for a clear theoretical construct of social support to be developed, one which recognizes the multi-dimensional nature of such support. Quantitative and qualitative evaluation is required, not only of informal and formal relationships, but also of the instrumental and affective components of social support.
 - Also needed are studies of social support as a predictor of the course of disease. A better understanding of how social support acts as a predictor may lead to the development of improved direct intervention studies.
 - The benefits of social support and its mechanism of action appear to vary according to the sex of an individual, and according to the disease concerned. These are areas that should be investigated.
 - Because social support may function to maintain good health (i.e., prevent deterioration) rather than to reverse poor health, persons with early rather than late disease should be studied. Also, studies should focus on conditions which are a major cause of disability.
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INTRODUCTION

The prevalence of chronic disease is rising steadily in the industrialized nations and will likely continue to do so as the mean age of the population increases. In the United States, arthritis and rheumatic conditions are the second most important chronic disease in terms of disability attributable to this cause (Wilder, 1976). In Canada, arthritis and rheumatism are the third most frequent cause of activity limitation, following other limb and joint disorders and heart disease (Wilkins and Adams, 1983).

The major arthritic and rheumatic diseases which result in disability are chronic and incurable. Increasingly, it has been recognized that the determinants of disability in persons with musculoskeletal impairments are not only medical, but also psychosocial and economic (Cunningham and Kelsey, 1984). Investigators have shown a heightened appreciation of the role of other than traditional medical determinants as factors in the causation, prognosis and treatment of arthritis and rheumatism. This has resulted in a renewed interest in the study of the role of social support in the promotion of both physical and psychological well-being.

What is social support?

The scientific evaluation of social support is a recent phenomenon and the definition of social support has evolved rapidly. Ten years ago, definitions of social support focused mostly on its emotional, or affective, dimensions. Cassel (1976) defined social support as the "metness" or gratification of a person's basic social needs (approval, esteem, succorance). Cobb (1976) conceived social support to be information leading a person to believe he is cared for and esteemed, and that he belongs to a network.

Subsequent investigators have added the notion of gratification of "instrumental" needs to Cassel's original definition (Thoits, 1981; House et al., 1982; Wallston et al., 1983). Accordingly, the social network, or providers of social support, have been identified by Thoits and others not only as a person's family, friends and co-workers who offer social support in informal ways, but also "institutional" givers of assistance, such as ministers, teachers, counsellors and other professionals whose contribution of social support may be more formal. Thus, the link between the giver and recipient of social support is not necessarily based on a "personal" relationship; it may also be based on a formalized social contract between giver and recipient. Examples of social support which would ensue from formalized relationships include payment of old age and disability pensions, provision of public schooling, and facilities to provide material as well as moral support to unwed teenaged mothers.

How is social support measured?

The current definition of social support describes a multi-dimensional construct. The translation of any multi-dimensional construct into a measurable entity is always problematic, and the operationalization of social support is not an exception. Several unique operational components of social support have been identified (Blazer, 1982; Donald et al., 1978; Wallston et al., 1983). These include quantitative and qualitative components.

The "quantity" of social support is assessed by objective measurement, typically by analysis of the amount or number of social contacts one has. Blazer (1982), for example, operationalized and measured quantity of social support as: 1. roles and available attachments – the number of first degree relatives of the subject; and, 2. frequency of social interaction – the number of telephone calls and visits with friends or relatives which had occurred in a week.

The "quality" of social support is assessed through subjective assessment, and is measured as the perceived adequacy of social support as reported by the recipient. Blazer measured the quality of social support by questionnaire items which assessed subjects' judgments about the adequacy of their personal contacts.

The distinction between the amount of social support and the perceived quality of social support is important. While some authors have assumed that social support promotes desirable outcomes, Lowenthal and Haven (1968) and McFarlane et al. (1984) have noted that social support can be deleterious: some individuals have a preference for only limited social interaction. Furthermore, the beneficial or adverse effect of support provided to any given individual may differ depending on the source, even though the quantity is similar. One person may derive benefit from support by family members, another by friends. Thus, in addition to the quantitative aspects of social support, a person's perception of both the adequacy and appropriateness of social support must be evaluated.

Mechanism of action of social support

The idea that social support has a generally positive effect on well-being is intuitively appealing, but the mechanism by which it does so remains uncertain. Social support may have a direct effect on the maintenance or improvement of health. Social support may also act directly to alter prognosis once a disease has developed. Berkman and Syme (1979) have theorized that social support has a preventive effect by increasing host resistance and, conversely, that the absence of social support (social isolation) serves as a risk factor for the development of disease.

The second major mechanism by which social support may exert its effect was proposed by Cassel

(1976) and Cobb (1976) -- the buffering effect. These authors hypothesized that social support helps to moderate or buffer the effects of illness or other stresses on one's psychological and physical state. Thus, individuals with effective support systems should be better able to cope with major life changes whereas those with less effective support may be more vulnerable.

Wallston and her colleagues (1983) have noted that the notion of buffering as the mechanism by which social support influences health is an oversimplification, and have suggested that multivariate models relating illness onset to level of support are preferable to the search for univariate effects. Several, more complex models have been proposed. Wheaton (1985) described a model which suggests that the stress-buffering effect is the result of an activation of support resources in the presence of stress. In this model, support is dependent on the level of stress, and is mobilized by increases in stress. Another theory suggests that a person's perception of support from others may lead to a more generalized sense of control, which may, in turn, be the factor which links social support to health (Minkler, 1986).

Empirical findings on social support

Wallston et al. (1983), in an extensive review of the literature related to social support and physical health, have reported that there is very little evidence to support the notion of an etiological link between social support and onset of disease, whether social support is conceptualized as having a buffering effect or a direct effect. They note that the studies which have examined this relationship have been conducted retrospectively and thus are methodologically weak.

In the literature which focuses on social support as a prognostic factor in the presence of disease, positive findings have been highly consistently reported (Wallston et al., 1983; Myers, 1975; Cohen et al., 1985; Rahe et al., 1964; Hyman et al., 1972). In the context of a variety of conditions including congestive heart failure, alcoholism, cancer, stroke, hypertension, old age and others, social support produced positive outcomes on physical endpoints. In these studies, social support was conceptualized sometimes as support which occurs naturally from family and friends, and sometimes as support which is delivered formally, usually by health professionals. Social support was variously measured as perceived support and as the frequency or amount of social interaction.

Relatively few studies have considered or attempted to measure the potential negative consequences of social support. Wallston et al. (1983) have pointed out that social support may foster dependency instead of recovery in persons undergo-

ing rehabilitation, and also that undue stress may befall families who are providing support. McFarlane et al. (1984) have reported that social support networks which were perceived as most helpful were smaller than those perceived as less helpful.

Problems with research to date

Major conceptual and methodological problems in the study of social support have been identified by leading investigators in the field. In the conceptual realm, studies of "social support" have often been studies of different issues, due to the variety of ways in which social support has been conceptualized and operationalized. Social support is a multidimensional concept, but often investigators have looked at different dimensions, or only parts of the whole.

Another important problem is the failure to distinguish conceptually between the social functioning of individuals, and social support provided to individuals. Dean (1986) and Henderson (1984) have pointed out the problem of potential confounding among the social support variables, psychological characteristics of the individual and psychological distress. Thoits (1981) and Blazer (1982) have identified the potential confounding of life events with social support as another problem. For example, the event of loss of a spouse is by definition a change (which may be either distressing or desirable) in social support, and may also produce changes in social support, by causing some friends and relatives to rally around the individual, and others to avoid him.

Other problems in the empirical investigation of social support concern study design. Kasl (1982) has pointed out the need to have an internal design which provides for adequate assessment of baseline health status, and an analytical approach which controls for the effect of initial status on later outcomes. Thoits (1981) and Wallston et al. (1983) have noted that cross-sectional and retrospective analyses of social support and health have not determined the degree to which poor health can influence the level of support, or vice versa. Kasl (1982) has also identified the limitations of the case control design in terms of the uncertainty associated with the recall of exposure events. This is particularly problematic when the measure of exposure is subjective, and even more so when the subject reporting exposure believes that particular conditions are known to give rise to the disease with which he is afflicted. For example, retrospective appraisal of the quality of one's family relationships would probably be a less reliable measure of exposure to stress in childhood than would a measure which ascertained marital breakup through separation, divorce or death. And the arthritic respondent who believes that stress is the

cause of arthritis may be more likely to report antecedent exposure to stressful situations.

PURPOSE

The purpose of this review was to identify, summarize and evaluate the results of published and unpublished papers related to the relationship of social support and the health of patients with arthritic or rheumatic disease. A broad definition of the concept of social support was employed, similar to that offered by Thoits (1981): the subset of persons in an individual's total social network upon whom they rely for socio-emotional aid, instrumental aid, or both. Ministers, teachers, counsellors and social workers may be members of the individual's social support system, in addition to family, friends and co-workers. Thus instrumental aid (e.g., material, educational) as well as socio-emotional aid were included as terms in the definition. Providers of social support included health professionals, formal agencies, employers and co-workers, as well as family members, friends and neighbours.

Myers et al. (1975) defined the concept "social integration" to include a number of variables, e.g., socio-economic status, marital status, job satisfaction. Because of the broad scope of social support as it has been defined for this review, Myers' notion of social integration perhaps more closely approximates the concept which is the focus of this review than do the usual definitions of social support.

Source of papers

To identify studies for this review a series of four computer-assisted searches of online bibliographic systems was carried out. (See Appendix 1 of the full report for a summary of search terms, databases and dates.) As relevant articles were compiled, their references were cross-checked. Review articles of the generic literature on social support were collected from the contents of reference files, and the references included in these articles were also cross-checked. Leading investigators who had published on social support in the rheumatic diseases were contacted by mail. They were requested to inform us of any relevant papers, published or unpublished, which did not appear on the list of references which we had compiled up to that time, and to call our attention to any work in progress in the area.

Data selection

Several criteria for inclusion of papers and abstracts in this review were established in advance. They required that:

- the paper report an investigation of some aspect of social support in relation to rheumatic disease;
- data and analytic techniques be reported in the paper;
- the study design be such that the temporal sequence of events permitted reasonably clear interpretation of cause-effect relationships;¹
- the paper be written in either the English or the French language

Validity assessment

A standardized appraisal form (see Appendix 2 of the full report) was developed for the detailed assessment of the papers which met the basic inclusion criteria outlined above. Each article was systematically summarized in terms of the following elements:

- design (classified as randomized controlled trial, cohort study prospective or retrospective, case-control study, or cross-sectional study);
- study population and setting;
- axis (risk factor, prognostic factor, maneuver, or outcome) of study of social support;
- study variables, or endpoints;
- measures; and
- findings.

Each paper was then evaluated for the presence of potential methodological weaknesses, according to previously established criteria (see Appendix 3 of the full report). In that the scientific evaluation of the effect of social support upon health remains in a developmental phase, it was elected to seek out only major methodological weaknesses that might imperil the validity of a study. Each paper was reviewed independently by two persons and differences were resolved by consensus.

Classification of social support

In the body of literature on social support and arthritis, social support is usually oriented in one of four axes. These axes are the etiological axis, in which social support is conceptualized as a risk factor which is related to the subsequent development of arthritis;

1. The consequence of this was the exclusion of those cross-sectional studies in which causal and outcome effects were not distinguishable from each other. Many of the "arthritic personality" profile studies are of this genre; difficulty arises in interpreting personality deviations from the norm as etiological or as consequential features of the disease process.

the prognostic axis, in which social support is conceptualized as a factor which predicts the future outcome of the arthritic disease; the axis of a maneuver or intervention, in which social support is conceptualized as an intervention variable affecting outcome of the disease; and the outcome axis, in which social support is the result of the interplay between other variables including the disease itself.

FINDINGS

Social support as a risk factor

In only a few studies was social support conceptualized as an etiologic factor in relation to arthritic and rheumatic disease. The findings of most of these studies were limited by major methodological weaknesses. Heisel (1972) and Henoch et al. (1978) found more evidence of major life changes or family instability prior to the onset of disease among patients with juvenile rheumatoid arthritis than among controls. As well, Henoch et al. found that significantly more persons in the juvenile rheumatoid arthritis group had been adopted by their parents than had persons in the control group. Similarly, Baker et al. (1982) also found that more persons among a group of adult rheumatoid arthritis patients reported antecedent stressful life events and family breakup through divorce, separation or death than did persons in the control group.

The findings of the studies by Heisel, Henoch and Baker contrast with an earlier investigation carried out by the Scientific Advisory Committee of the Empire Rheumatism Council (1950) in Britain. This study found no differences in levels of exposure to adverse conditions at home or to psychological factors such as shock, worry or trauma between a group of rheumatoid arthritis patients and a group of controls.

All four of these studies employed a case-control design and are subject to recall bias. As Baker notes, "it is also theoretically possible that some of the life events were influenced by a change in the patient brought about by a non-specific prodromal phase of the illness before joint symptoms became manifest." Thus, to attempt to discern the temporal sequence of events can be nearly as problematic in case-control studies as in cross-sectional studies. Because of their subjectivity, retrospective accounts by subjects of their relationships with their mothers (Baker) or their home conditions during childhood (Empire Rheumatism Council) were particularly susceptible to recall bias. Heisel's and Henoch's use of more objective exposure indicators of family relationships (divorce, separation, death) lessened the likelihood of such bias in their studies.

Additional problems noted in these studies were the choice of an inappropriate endpoint (probable

rheumatoid arthritis; Baker), the failure to use blinding in assessing outcome (Baker), inconsistency in the definitions of study outcomes for cases and controls² (Henoch), and inadequate (27% loss) follow-up (Henoch). The paper by Heisel contained insufficient information to assess the rate or adequacy of follow-up.

Nagi et al. (1973) examined a probability sample of persons aged 18 to 64 residing in Columbus, Ohio, and found an inverse linear relationship between educational attainment and the prevalence of back pain. Unfortunately, the data were not adjusted for age, which is important, because educational attainment tends to be lower in older persons, and could therefore confound the relationship between education and back pain. In addition, the assessment of psychological factors, many of which could result from back pain, may have confounded the outcome of the study.

Pincus et al. (1987) examined data from the Health Interview Survey in the United States for persons aged 18 to 64, and found a strong inverse linear relationship between educational attainment and the age-adjusted relative risk of musculoskeletal disease. Although the survey data were cross-sectional, the findings suggest a risk factor relationship between the variables because education was presumably completed in early adulthood, before the onset of arthritis.

In summary, in several of the studies presented above, it was difficult to distinguish the impact of stressful events on the outcome from the impact of impaired social support. The evidence to support the notion of a causal relationship between impaired social support and subsequent rheumatic disease is not conclusive, but the findings which relate low educational attainment to increased risk of disease are compelling. The mechanism of action by which low education might predispose persons to disease is not known. Berkman and Syme (1979) have proposed that psychosocial factors (stress) influence susceptibility to various disorders. Evidence shows that the prevalence of high levels of stress and social isolation is much greater among persons with low education than among those with higher levels of education (Ruberman et al., 1984). Thus, low educational attainment may serve as a marker for the presence of stress and social isolation.

Social support as a prognostic variable

Studies have focused on some aspect of social support as a predictor of various behaviors and outcomes for arthritic patients. Oakes et al. (1970)

2. Population controls were assessed for exposure at only one point in time, while cases were assessed over a period of time.

and Ferguson and Bole (1979) studied the relationship between perception of family support in arthritic patients and their compliance with prescribed treatment regimens. Oakes et al. found that the perception of positive family support increased the likelihood of subsequent patient compliance with splint-wearing. In contrast, Ferguson and Bole found that perceived family support did not predict compliance with recommendations related to medication, exercise and splint-wearing. The cross-sectional design of the Ferguson and Bole study may limit interpretations of the study findings.

The findings on family support in relation to psychosocial adjustment are more consistent. Potts and Brandt (1983) found that self-reports of coping with their disease among patients with rheumatoid arthritis were strongly related to their perceptions of family support. In a study of patients with systemic lupus erythematosus (Stein et al., 1985), support from family and friends was reported as the most important determinant of patients' psychosocial adjustment. Potential differential prognostic susceptibility between the study groups limited the interpretability of the Stein study. Controls were the population of British Columbia, but not enough information was given to know where the study subjects resided. If, for example, they were all from urban Vancouver, they would have been dissimilar to the controls in ways which might have affected the study outcome.

Two studies examined the relationship between perceived social support and concurrent or subsequent health status in arthritic persons. In a group of elderly women with osteoarthritis who were surveyed for a period of six months, increases occurred over the study period in both functional capacity and perceived level of social support (Weinberger et al., 1986). However, no statistical correlation was found between these variables.

Rimon and Laakso (1985) examined the rate of exacerbation which had occurred over a 15-year period in a group of 74 women with rheumatoid arthritis. For the subgroup who reported at diagnosis that in the preceding year they had had an emotionally traumatic event which precipitated a psychic reaction, the rate of subsequent exacerbations was significantly higher than for those who had reported no such history. Unfortunately, neither the exposure (life stress) nor the outcome (exacerbation) was clearly defined, and the latter was not assessed blindly.

Several studies have addressed the issue of social support in relation to work disability. An early study conducted by Natvig (1970) in Oslo showed a positive predictive relationship between "good family situation" and the likelihood of subsequent return to work in a group of men undergoing a vocational rehabilitation program.

Findings from studies conducted in the United States by Yelin and colleagues (1980) have shown that the level of premorbid individual income predicted disability. The probability of disability among persons whose income was below the mean income of the study group was .66, compared to a probability of disability of .49 among persons whose income was above the mean. They also showed that being married clearly decreased the likelihood of return to work for arthritis patients. The latter finding contrasts with that of Sheppard et al. (1981) who found that among persons receiving counselling, married persons were more likely to be employed after the program than were single persons.

Studies of determinants of work disability among rheumatoid arthritis patients by Yelin and his colleagues have consistently shown that the strongest predictor of remaining on the job after the onset of illness is the worker's level of autonomy at the workplace. Discretion over the pace of work, and over particular work activities, were shown to be much better predictors of work disability than were medical factors such as duration of disease, presence of comorbid disease, stage of disease or surgery, or than participation in vocational rehabilitation programs (Meenan et al., 1981; Yelin et al., 1980; Yelin et al., 1987).

Studies which have examined work disability in patients with rheumatoid arthritis in terms of educational attainment as a prognostic variable have shown that educational attainment strongly predicts the likelihood of returning to work (Robinson and Walters, 1971) and of returning to one's previous employment (Urbanek et al., 1984). However, analyses of work disability which included variables related to work characteristics together with variables related to educational attainment (Yelin, 1980) indicated that educational attainment is more likely an indicator of the type of job one has than a direct determinant of disability or return to work. In models containing both variables related to personal characteristics, including education, and variables related to job characteristics, job characteristics were by far the strongest predictor of employment among rheumatoid arthritis patients. By occupational category, arthritics who were employed as professionals and managers were least likely to stop work, while service workers were much more likely to become unemployed (Yelin et al., 1980a, 1980b; Meenan et al., 1981; Yelin et al., 1987).

In a carefully conducted nine-year follow-up study, Pincus and Callahan (1985) examined mortality and morbidity in relation to educational attainment for a group of 75 adult rheumatoid arthritis patients. They found that formal educational level independently predicted mortality

and declines in functional capacity, even after controlling for age, duration of disease and all other variables studied.

Social support as a maneuver

Several studies examined the manipulation in arthritic patients of some aspect of social support to determine effects on predefined endpoints. In many of these studies, social support assumed the form of some type of group counselling or teaching.³

Some, but not all, of these papers reported favourable outcomes on at least some of the endpoints which were studied, although most of the studies were weakened to some extent by a variety of design faults. Improvements in disease activity, joint deformities, pain or functional status were attributed to a variety of interventions in studies by Lorig (1985a, 1985b), Bradley (1984), Shearn and Fireman (1985) and Feinberg and Brandt (1984). However, Bitter (1987), Parker et al. (1987), Strauss et al. (1986), Kaplan and Kozin (1980), and Cohen et al. (1987) showed no effects of interventions on disease activity and functional or clinical status.

Small sample sizes limited the findings of some studies (Bradley, Parker); insufficient follow-up or dropout rates which exceeded 20% limited others (Shearn and Fireman, Strauss, Kaplan and Kozin, Feinberg and Brandt). In one study (Bitter) randomization was not used in the assignment of subjects to experimental and control groups, which provided the possibility of dissimilar prognostic susceptibility between the groups at baseline. In the study by Feinberg and Brandt, several problems were present. Failure to use blinding in assessing outcome led to the potential for surveillance bias. Probable dissimilarities in prognostic susceptibility between the study and control groups was also an issue in this study. The duration of disease, a variable which has been shown to independently predict many of the same outcomes which were established as endpoints in the Feinberg and Brandt study, was ten years for the control group, but five years for the experimental group. In addition, the two study groups were from different institutions. Finally, the loss to follow-up was excessive in this study; (50% loss from the experimental group, and 35% loss from the control group).

Increases in disease-related knowledge among arthritis patients were reported in intervention studies by Cohen et al. (1987), Lorig (1985a), Knudson et al. (1981), Kaplan and Kozin (1980), and Vignos et al.

3. There is a substantial body of literature which reports the results of various educational programs among RA patients (see Mullen et al., 1987; Lorig et al., 1987). From this literature, those papers which addressed some aspect of the issue of social support were included in the present review.

(1976). Improvements in attitudes toward disease, in coping with disease or in psychosocial adaptation to the disease were found in intervention studies by Lorig (1985a) and Feinberg and Brandt (1984), but no changes in these variables were observed in studies by Potts and Brandt (1983), Strauss et al. (1986), and Shearn and Fireman (1985). Small study samples limited the findings of the Knudson study, and excessive dropout rates limited the studies of Kaplan and Kozin and Feinberg and Brandt. The problem of differential prognostic susceptibility which was present in the study by Feinberg and Brandt was also present in the studies by Potts and Brandt and Knudson.

Parker et al. (1987) studied the effects on pain self-management of a cognitive-behavioural pain management group therapy program among rheumatoid arthritis patients. Long-term treatment effects were found in subjects' ability to divert attention from pain, perception of control over pain, and ability to decrease pain. Knudson et al. (1981) as well as Lorig (1985a, 1985b) reported improvements in self-management behaviours among arthritic patients who followed their respective programs.

No changes in depression or life satisfaction were effected by intervention programs reported by Shearn and Fireman (1985), Cohen et al. (1987) and Kaplan and Kozin (1980), although Bitter (1987) reported significant reductions in depression and anxiety after group therapy (among subjects who were not randomly allocated to the treatment group).

Increases in employment rates for arthritics have been attributed to work-counselling programs as reported by Sheppard et al. (1981) and Natvig (1970). Neither study, however, used a control group.

There is clearly no consistency among the findings of intervention studies, which partially reflects the variety of the programs studied, as well as the methodological weaknesses present in many. Group program approaches which were reported to produce generally positive changes included the Arthritis Self Management Program (Lorig, 1985a, 1985b), a lecture and assigned reading (Vignos et al., 1976), biofeedback assisted cognitive-behavioural group therapy (Bradley, et al., 1984), and a six-part series of educational seminars (Knudson, et al., 1981), although the small size of the study groups in the latter two studies prevented conclusive evaluation of the program.

Group approaches which produced limited improvements included instructor or counsellor-led patient discussion groups (Potts and Brandt, 1983; Kaplan and Kozin, 1980), programmed mutual support and social support groups (Bradley et al., 1984; Parker et al., 1987; Shearn and Fireman, 1985), and conventional group psychotherapy and group assertion relaxation therapy groups (Strauss et al., 1986). Methodological weaknesses were present in all these studies and have been discussed above.

A replication of Lorig's intervention with the Arthritis Self Management Program conducted by Cohen et al. (1986) showed that in contrast to Lorig's findings, the intervention was no more effective than non-intervention in lessening patients' pain, improving their functioning, enhancing social support systems, or lessening depression.

It is interesting to note that in all the intervention studies where information was presented on the educational attainment of study participants, the level of education was substantially higher than the level of education for the United States population. In 1978, 33% of Americans had any education beyond grade 12 (Pincus, 1987). However, 61% of subjects in the Strauss study, and 75% of subjects in the Knudson study had more than 12 years of education. In several studies, educational attainment was expressed as mean years of schooling. In the study by Shearn, subjects averaged 13.5 years of schooling; in the study by Lorig they averaged 14.6 years; and in the Cohen study the average level of schooling among the subjects was 16.2 years. Because the interventions were tested on groups of persons whose educational characteristics were not representative of the general population, the generalizability of the findings of these studies is probably limited.

The mechanism of action of social support, either "natural" or programmed, upon health outcomes is poorly understood. As Lorig et al. (1987, unpublished) has recently suggested, the assumption that increase in knowledge leads to favourable change in behaviour and subsequent improvement in health status may not have any empirical basis. In testing her own data on persons who had undergone the Arthritis Self Management Program, Lorig found that increases in knowledge occurred. However, an increase in knowledge did not result in a corresponding change in behaviour or health status. Also, while increases in social support and in health status occurred, the change in the level of social support was not predictive of change in health status. Correlations of health outcomes with perceived ability to cope (self-efficacy) were far higher than they were with adopting taught behaviours (Lorig et al., 1987, unpublished; Holman and Lorig, unpublished.).

Social support as outcome

Follow-up studies of juvenile rheumatoid arthritis patients, juvenile dermatomyositis patients, and systemic lupus erythematosus patients have shown that the social circumstances of the subjects, including educational attainment, employment history, family structure and lifestyle were comparable, for the majority of subjects, to the social status of the general population (Hill et al., 1976; Chalmers et al., 1982; Miller et al., 1982; Stein et

al., 1985). Disability persisted more frequently among female patients with juvenile rheumatoid arthritis than among males (Miller et al.). In the studies by Hill, Chalmers and Stein it is possible that the choice of controls was inappropriate. In all three studies, the general population of the province of British Columbia was used to draw comparisons with the study groups which appear to have been comprised mostly of persons living in the city of Vancouver.⁴ However, important differences in social characteristics, circumstances and opportunities have been shown between persons residing in city areas and those residing in rural areas. The choice of general population controls might thus have inflated the favourable outcomes reported in these studies. In the studies by Hill and Miller, losses to follow-up exceeded 30%.

Julkunen et al. (1981) found similarly good social adjustment among patients with osteoarthritis and those with soft-tissue rheumatism. Using a case-control design, these investigators found no differences between either group of cases and non-diseased controls with regard to employment status, although the osteoarthritis patients reported significantly lower levels of satisfaction with their work. Yelin et al. (1987b), however, found that for a cohort of patients with rheumatoid arthritis, functional ability had been lost or impaired in all seven domains of activity which were studied. These included household chores, shopping, social relationships, religious activities, leisure, public service and work. Patients with osteoarthritis were limited in their ability to perform household chores, shopping and leisure activities. Lubeck and Yelin (1987, unpublished) surveyed the same study panel of arthritic patients together with a group of healthy controls as to the importance to them of each of these activity domains. Social relationships were considered the most important of all activities for all groups, and work the least important. This finding emphasizes the importance of the burden of disease for the rheumatoid arthritis patients, whose activity losses included those related to social relationships. Deyo et al. (1982), in a study of the impact of rheumatoid arthritis on physical and psychosocial function, found that psychosocial adjustment correlated positively with duration of disease; suggesting that psychosocial adjustment improved with longstanding disease.

In an earlier study (Meenan et al., 1978) 76% of a group of 50 Anatomic Stage III rheumatoid arthritis patients reported major changes in employment due to their disease, and 58% had at least one major psychosocial cost due mainly to disease. Psychosocial costs included marital disruption,

4. In the Stein study it is not clear where in British Columbia the patients lived.

change in family structure, change in family income, change in place of residence, and major psychiatric problems.

Two randomized clinical trials examined changes in social role or adjustment in relation to structured programs. Vignos et al. (1972) reported that a group of arthritic patients, for whom complex care plans were devised by a multi-disciplinary health care team and then implemented by a home visiting nurse, showed significant improvement in social adjustment at the end of one year, in comparison with arthritics who had received usual care. Parker et al. (1984) studied a group of males hospitalized with rheumatoid arthritis who had received an intensive education program delivered by rheumatology patient educators. They found that for a number of endpoints, including social role, the program had no effect. It is interesting to note that in comparison with a control group, the treatment group in this study showed that their disease-related knowledge had increased subsequent to the program, but also that their activity level was significantly more impaired and their pain scores were significantly higher.

RECOMMENDATIONS FOR FUTURE RESEARCH

General recommendations

There are several basic requirements for future research in the area of social support and arthritis.

Design:

The preferred study designs for the study of social support in arthritic patients are randomized controlled trials or prospective cohort studies. Intervention studies should in general use a randomized design. Special effort is required to avoid specific problems which have been noted in the literature. These include:

- inadequate control for baseline differences in variables known to be prognostic, e.g., sex, disease duration, health status, and disease severity;
- inadequate follow-up;
- choice of primary predictors, maneuvers or endpoints likely to be confounded by the measure of social support used; (For example, for social support as a predictor of psychological outcome, the outcome measure should not include social contact as a measure of psychological status. In general, a measure of physical status may be a better variable to contrast with social support.)

- insufficient sample size, resulting in failure to detect a difference which is really present;
- inappropriate or invalidated instrumentation;
- inappropriate choice of controls, resulting in dissimilar prognostic susceptibility of study groups at baseline;
- failure to use blinding in assessment of study outcomes;
- heterogeneity of study population. The probability of Type II error is also increased by heterogeneity of the study group, as the distribution of study effects may not be distributed normally (Lorig et al., 1987a).

Theoretical construct of social support

There must be a clear theoretical construct of social support. Issues requiring special attention include:

- recognition of the multidimensional nature of social support is required in formulating a theoretical construct. Evaluation of quantitative and qualitative aspects, of informal and formal relationships, and of instrumental and affective components of social support should be carried out.
- evaluation of interrelationships of measures over time is needed. For example, social support may alter because of life events or because of changes in disease activity.

Specific recommendations

- Studies of the psychosocial costs of diseases are of descriptive value. In contrast, studies of social support as a predictor of disease course or as a direct intervention appear desperately needed. Better understanding of how social support functions as a predictor may permit the development of better intervention studies.
- The benefit and mechanism of action of social support appears to vary with the sex of an individual and may work differently in different diseases. Disease-specific studies with due attention to known clinical distinctions (e.g., rheumatoid factor negative and rheumatoid factor positive rheumatoid arthritis) are required.
- Studies should focus on conditions which are a major cause of disability.

- Because social support may function to maintain good health (prevent deterioration) rather than to reverse poor health, it is better to study persons with early rather than late disease.

SUMMARY AND CONCLUSIONS

The purpose of this review was to summarize the literature on the interrelationship of social support and the patient with arthritic disease. The major findings were:

- Similar to the studies of social support as a risk factor for non-arthritic diseases, there is little evidence corroborating social support as a risk factor in arthritic and rheumatic diseases, although low educational attainment is strongly predictive of risk of these diseases. While the evaluation of social support as a risk factor in arthritis would not appear to be a priority, to be properly undertaken it would require large cohort studies with close medical follow-up. Arthritis would be only one of the medical outcomes.
- Findings on the role of social support as a predictor of the arthritic patient's compliance with prescribed treatment, and as a predictor of clinical status, are inconsistent.
- Perceived family support consistently predicts positive psychosocial outcomes in arthritic patients.
- The degree of susceptibility of individuals to the consequences of their disease is determined to an important extent by their level of educational attainment; the ability to cope with the disease is higher among persons with more education.
- Social predictors of work disability for arthritic persons include family income, education and, probably most importantly, job characteristics.
- In general, intervention programs for arthritic patients which involve "cognitive-behavioural" and other "self-control" instruction have been somewhat more successful in effecting positive changes in behaviour and health status than have non-directive mutual support and discussion group programs.
- The long-term social adjustment of persons with juvenile rheumatoid arthritis, systemic lupus erythematosus, and osteoarthritis may be less adversely affected than that of rheumatoid arthritis patients. Rheumatoid arthritis has a major impact on the social functioning of the majority of affected patients. Descriptive studies of outcome would be of value in determining target diseases with high psychosocial costs.

MUTUAL AID AS A MECHANISM FOR HEALTH PROMOTION AND DISEASE PREVENTION*

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***Summary version**

HIGHLIGHTS

- Mutual aid/self-help (MASH) groups are voluntary, small group structures that are usually formed by persons with a common handicap or problem, for the purpose of providing emotional support and mutual assistance, and bringing about social and/or personal change.
 - The recent proliferation of MASH programs is thought to represent both a public response to unmet social and health needs and a professional response to growing research evidence of the beneficial influence of social support in protecting health and preventing illness.
 - The role of social support in moderating the impact of stress on health is not understood. This is currently a major area of investigation in stress research, from both an etiological and a treatment perspective.
 - Mutual aid is only one form of social support, but its potential for interrupting the causal link between stress and illness is considered unique. The processes, rather than the activities, of mutual aid are thought to be important, but there has been little systematic research into the relative usefulness of different mutual aid processes.
 - Gaps in scientific knowledge about social support apply equally to mutual aid. Areas of special concern are:
 - the influence of various intra-personal and environmental factors
 - the respective functions and benefits of natural versus artificially provided social support
 - the development of instruments to measure different kinds of social support
 - program evaluation research
 - the benefits of helper therapy
 - formal studies of the impact of mutual aid on health, coping and adaptation in different contexts.
 - There are serious methodological barriers to studying the effectiveness of mutual aid. Randomized controlled trials of true self-help groups are impossible; there are concerns about protecting anonymity and privacy, and altering the natural helping process; and MASH groups themselves have little interest in measuring impacts, keeping records, etc.
 - Successful mutual aid research requires investigators who possess high-level technical evaluative skills and who are "sensitive politicians and communicators".
 - Assessment of the impact of MASH interventions should not be limited to measuring pre- and post-test symptoms. Many kinds of measures are required, e.g., the attributes of the social network; the amount, source and type of social support; the repertoire and choice of coping strategies; goal expectations and attainment; reduction of stress; quality of life and satisfaction; reduction of stigma, etc.
 - Methods must be found to incorporate informal helping approaches and mutual aid strategies into planning for human services. This must be done without either coopting them as adjunct services under professional control, or regarding them as a cheaper substitute for health and social services.
 - Mutual aid remains on the fringes of the health care system, and the literature provides no definitive answers or simple guidelines to help policy-makers and planners bring it into the mainstream. Indeed, more assessment of its implications is needed before large-scale policy changes can be undertaken.
 - Nevertheless, Health and Welfare Canada should endorse mutual aid more strongly and definitively, and promote further research and related programming, e.g., by funding research into its health benefits, including demonstration model program development; by educating policy-makers and planners on the subject; by obtaining national base-line data on mutual aid programming; by gathering and disseminating information; by training health and social service professionals; and by developing policies that recognize the interdependence of mutual aid with other framework cells.
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INTRODUCTION

This report is a brief synopsis of the burgeoning and diffuse literature on mutual aid a vast collection of empirical, descriptive, analytical and theoretical material spanning its nature, properties and processes; its sources, mechanisms and forms; its uses, providers and recipients; its impact and benefits; its inter-relationships with professionals and formal systems; and the recommendations of experts about current and future needs with regard to programming directions, research and social policy.

Review of this literature represents an enormous bibliographic and analytic exercise. During the last two decades, scientific interest in the causal influence and the applications of social support and mutual aid (its most unique, visible and fastest growing organized form) has been extremely high. Furthermore, a wide variety of health and social science professions and lay groups have contributed to the knowledge pool. All have their own particular perspectives, approaches and priorities and publish in their own journals.

Thus, the project team has prepared a comprehensive report which is provided under separate cover together with an extensive bibliography. The aim here is to detail its main conclusions, with particular emphasis on gaps in research knowledge, methodological considerations, suggested indicators which should be applied, needs for data, priorities for research, and political and social considerations.

DEFINITION

Mutual help (aid) occurs only when the helper and the person being helped share a history of the same problem. The essence of the process is mutuality and reciprocity. The helper may not be a peer in any other sense, of the person being helped, but he or she is a 'survivor' who, having coped successfully with the problem has acquired a useful experience based on practical experience rather than special education ... Moreover, the sharing experience benefits both the person being helped and the helper" (Silverman, 1980, p. 9)*.

People have always understood, almost intuitively, that individuals in one's social network who have "been there" themselves often have a special understanding and wisdom about particular life stressors, and that to seek or accept advice and support from these "veterans" may be a very beneficial coping strategy. Examples of mutual aid and its application to key areas of societal concern can be found in every phase of the history of mankind. However, in complex and mobile post-industrial societies like Canada,

this source of help may not be as readily available from families, neighbours and other informal sources at times when it is most needed.

The proliferation of mutual aid/self-help programs in the past two decades is thought to represent both a public response to unmet social and health needs and a professional response to growing research evidence of the beneficial influence of social support in health protection and illness prevention.

FORMS OF MUTUAL AID

Although there are a variety of formal program models for supplying mutual aid, mutual aid/self-help (shortened to MASH) groups have received the broadest public attention.

MASH groups are defined as voluntary, small group structures usually formed by persons with a common purpose. The groups come together to provide emotional support and mutual assistance in "overcoming a common handicap or life-disrupting problem, and bringing about desired social and/or personal change (Katz and Bender 1976, p. 9).

The literature provides ample evidence of broad support for this definition. However, our choice of the term "mutual aid/self-help" reflects the current confusion, lack of clarity and divergence of opinion about definitions and language. Because this problem permeates all aspects of this field and acts as a barrier to research, a glossary of definitions and concepts is provided in an appendix.

The terms "mutual aid", "mutual help" and "self-help" are used in the literature in an apparently interchangeable sense to describe the kind of formal group defined above. However, the concepts of reciprocity and interdependency are fairly explicit in two of the terms while the strict meaning of "self-help" is provision of aid to oneself. Yet it has come to be defined much more broadly as a social movement phenomenon which spans self-help groups, other lay organizations aimed at new social forms of coping and humanization of health and social services, and various forms of alternative care. "Self-help" must also be distinguished from "self-care"; the latter term encompasses personal health care activities that are often carried out on an ad hoc basis in natural, private settings, and it does not necessarily imply an organized purposeful approach involving mutual aid.

The literature is also characterized by differences of opinion about the criteria to be used to define

*All references cited in this summary paper are available in two forms: either with the full report, or in a separate list (for information on how to obtain reference lists, see page 8).

the outer boundaries of mutual aid/self-help groups, beyond which they should be viewed as some other type of service or therapy. Europeans view "self-help" groups in the health field as more explicitly grounded in principles of health care and as not excluding professionals to the same extent as North American groups. In U.S. and Canadian literature, the assumption is often made that professionals are never directly involved in true "self-help groups", that there are no fees for service, and that they must never be controlled by formal agencies. However, closer examination of program descriptions provided in the literature reveals that this latter qualification is the only one about which there seems to be some consensus.

Some assert that it is not possible for outsiders to make arbitrary decisions about what is or is not mutual aid/self-help. There will be exceptions to every rule and only group members can truly decide whether they are a MASH group. However, it is agreed generally that use of the term should be restricted to those programs that address people with *personal* difficulties or problems, as opposed to those directed toward economic reform, foundations engaged in research, voluntary organizations, etc.

Other formal types of mutual aid include *mutual aid networks* (which are not organized to the same extent as MASH groups but promote mutual support); *dyadic support interventions* (therapeutic partnerships which deliberately create "buddy systems", peer helpers and peer leaders or tutors, one-to-one support provided by an indigenous lay companion, etc.); and *support groups* (a generic term encompassing a wide range of specific therapeutic modalities, such as disease management and psycho-educational groups, all of which feature the active involvement of professionals and sharing and benefitting from like experiences by participants).

MUTUAL AID: ITS ROLE IN A CONCEPTUAL FRAMEWORK FOR HEALTH PROMOTION

The Stress-Illness Pathway

In order to appreciate the potential importance attached to mutual aid as a mechanism for prevention and health promotion, the current state of knowledge about the stress-illness causal pathway and the influence of social support at various points along its route must be examined.

During the past two decades, the findings of many studies have demonstrated causal associations between the experience of a range of life stressors and susceptibility to illness and accident rates in general and a number of diseases in particular. However, despite the repeated finding of a statistically significant temporal relationship be-

tween life events and illness, the correlations between the two have been consistently low. This finding has been explained by the complex interplay between factors in the person and factors in the environment (and in some cases a disease agent) in the occurrence of illness, or conversely in its prevention. A host of individual characteristics (including cognitive appraisal and coping styles, internal versus external locus of control, personality factors, self-efficacy, etc.) have been found to act as intervening variables. The importance attached to coping is reflected in the fact that Health and Welfare Canada has requested a separate report on its influence. Coping is a multi-dimensional construct which includes social support—viewed as a crucial environmental coping resource. As efforts to manipulate external coping resources have to date been much more fruitful than those aimed at internal factors, the role of social support has become one of the top fields in stress research today, both from an etiological and a treatment perspective.

The Causal Influence of Social Support

Rapidly accumulating published reports offer increasing evidence that social support and social networks (two distinct concepts) are causally linked to various indices of health status (for reviews, see Broadhead, 1983; Wallston et al., 1983; Berkman, 1984; Gottlieb, 1983A and 1988 in press; Cwikel and Israel, 1988 in press). The findings to date suggest the potential for both a "main effect" and a "buffering role" in the protection of health and prevention or moderation of illness (see, for example, Lin and Dean, 1984). However, most reviewers state that there is still insufficient epidemiological evidence drawn from adequately designed experimental interventions, and they point to numerous unresolved questions about specific aspects of cause and effect (e.g., sources, forms, mechanisms, processes, timing, level, target populations, etc.).

Problems in the creation of a sound conceptual framework arise from the continuing differences in understanding and opinion about the operational definition, meaning, properties, sources and mechanisms of social support. There are many definitions for "social support", some incorporating mutuality as a central concept. However, most authorities agree that the terms "social support" and "mutual aid" are not synonymous, contrary to the implications of the general wording in the Framework for Health Promotion document. Social support encompasses a much broader array of informal and perhaps formal sources and avenues for support.

Current research on social support focuses on understanding the construct (its elements, composition, domain, etc.), unraveling the mechanisms through which it operates, and measuring its im-

fact. All investigators in this field experience major problems in developing methodological designs for studies to investigate social support because of its ubiquity in our lives, its dynamic as opposed to static properties, and the impossibility of isolating and controlling social support transactions. Measurement problems are exacerbated by the lack of consensus about definition, insufficient knowledge about the process, and the influence of other potentially important confounding variables such as personality. The various schools of thought, approaches and definitions with regard to social support have resulted in an array of measures, most of which have inadequacies in terms of reliability and validity. Experts note that until progress can be made in developing reliable, valid instruments and reconciling contrasting measures, few confident pronouncements can be made about the specific role of social support in moderating the impact of stress on health.

Mutual Aid and Health

Three major strategies for interrupting the causal link between stress and illness have been identified: decreasing stressors, reducing vulnerabilities, and increasing social support. Although mutual aid comprises only one form of social support, its properties and its potential are viewed as unique and particularly broad in scope. By their very nature, MASH groups have two core preventive features: they provide a range of social support, and they increase coping skills and repertoires through information and sharing experiences. Indeed, the processes and activities of these groups commonly encompass all of the identified types of social support — i.e., informational, emotional, instrumental and appraisal.

Mutual aid can be employed in a number of ways: as an alternate caregiving system, as an adjunct to the professional caregiving system, and as an independent element in interdependent networks of formal and informal care systems. In some cases (such as birth, aging, death or other life cycle event) it may be the help of choice.

MASH groups tend to address very specific and concrete problems. Those operating within the broad parameters of the health field are most frequently centred on coping with incurable or chronic medical conditions. However, whatever the disease or disability, members typically believe strongly that their concerns should not be addressed solely in medical or social terms, and that their needs do not fall exclusively under the domain of any one profession or organization. Many groups have been started by fellow sufferers or family members because of their long-standing dissatisfaction with traditional services. In some cases, organized service systems do not consider psychosocial concerns to be relevant or important. Some groups were founded in response to

medical advances that improved survival rates or reduced the need for institutionalization. All major disease categories listed by the World Health Organization are represented by MASH programs, as are all stages of human development and almost all of the imaginable life crises. In addition, the number of international disease-specific organizations that carry out and coordinate world-wide activities is growing rapidly.

MASH GROUPS — CHARACTERISTICS, PROCESSES AND ACTIVITIES

An enormous literature describes the attributes of these groups. With respect to typologies, any attempt to develop a comprehensive, foolproof system for classifying and describing MASH groups is doomed to failure; there will always be critics of specific methods and programs that do not fit the chosen categories. The problems, the target populations they address, and their methods vary widely. However, their core characteristics are very similar. They include: common experiences of members; mutual exchange of help and support; the helper benefits by helping; collective will-power and belief; provision of information, education, and anticipatory guidance; and constructive action towards shared goals.

The formats and techniques used by MASH groups are wide-ranging and idiosyncratic, depending highly on the personal experiences and beliefs of founders and members of what is needed and what works. They all equip themselves with an organizational structure, elect officers and devise special procedures for organizational continuity. The basic activities common to most MASH groups include emotional support, information and practical advice, direct services, social activities and pressure group activities. However, the processes of mutual aid are much more important than any particular activity. Much is written about these processes, which include universality, acceptance of the problem, hope that the problem can be dealt with, cognitive restructuring, helper therapy, role modeling, vicarious learning, desensitizing, social comparison, collective ideology, empowerment, self-care and personal control. However, there is very little systematic research into the relative usefulness of these processes.

RESEARCH

Introduction

The problems involved in research into mutual aid are a microcosm of those already discussed with respect to social support research, although there are some additional difficulties unique to mutual aid. However, despite formidable obstacles,

researchers have conducted and published results of a very large number of investigations. Although most are descriptive in nature and all can be criticized on their individual merits, the quality of the evidence is improving over time.

Research Activities

With one or two exceptions, empirical research did not begin to be published until the 1960s. Since then, the number, variety and scope of questions addressed by investigators have become so large that space constraints prevent their complete discussion here. Some areas of particular interest are outlined briefly, with Canadian studies used as examples where possible.

1. Who uses MASH programs? Study findings (e.g., Vachon et al., 1980) indicate that, like traditional health services, MASH programs are used less by lower socio-economic groups, ethnic minorities and men. Many reasons for the lower utilization rate by these groups have been advanced. Immigrants and the poor may feel disadvantaged in social skills and powerless, whereas men are not socialized to share feelings and stresses with others. A number of suggestions are made for achieving their greater involvement. For example, groups developed along more homogeneous lines appear to be more successful, and men may prefer a more structured format and cognitive problem-solving approaches.

2. Characteristics of members of programs, their concerns and views: While a cross-sectional design does not permit causal inferences, shedding more light on the characteristics of those who use these groups is a worthwhile objective. A large number of such studies have been published. Canadian illustrations include surveys conducted by Romeder (1982) and Gottlieb (1982). Others studies, while not experimental, have longitudinal designs which permit descriptions of member characteristics, the systematic documentation of reactions to the problem that led them to seek intervention, and before/after responses to the mutual aid program (e.g., Rogers et al.) with families of suicide victims (1982) and new amputees (1977-78).

3. Characteristics of groups, their communication patterns, processes and activities: These consist mostly of descriptive studies but some comparisons with other groups are reported (e.g., Wollert, 1986A). Toro et al. (1987) compared the social climate of psychotherapy groups with that of GROW self-help groups for those with emotional problems and found these two types of groups to be significantly different on most dimensions. Findings (e.g., Gottlieb 1982) suggest that for many members, MASH groups exert a significant impact on their social networks because of the extent of co-member involvement.

4. Relationships between MASH programs and professionals and formal health and social service organizations: Numerous studies have investigated this aspect from the perspective of members, or organizations, or both (e.g., Remine et al. 1984). More recent findings suggest a general climate of cooperation, interchange and cross-use among a majority of groups and by most individual members and professionals surveyed.

5. Studies of the characteristics of group leaders and the impact of serving as a "helper" in MASH groups: Results of studies suggest that more active members and those in "helper" or leadership positions may derive added benefits, but more study is needed.

6. Comparative Studies: Randomized controlled trials cannot be used to test the effectiveness of true MASH programs. When an experimental situation is created wherein the manoeuvre is standardized and assessed systematically, it ceases to become mutual aid (Powell, 1987). However, there have been evaluations of interventions which adhere to the MASH model but have been artificially launched by professionals (e.g., Vachon et al., 1980, with new widows). Lieberman and Bliwise (1985) conducted a controlled study of a "growth group" for the elderly whereby subjects were randomly assigned to groups led either by professionals or trained lay persons (a waiting-list control group was used). Professionally led groups were found to have a greater impact on improvement assessed on mental health indices. Comparative designs used to assess European disease management self-help groups (Bremer Schulte, 1983) and programs for bereaved populations (Videka-Sherman, 1982) report beneficial results on a variety of health indices.

7. Cohort Studies: A few studies have examined MASH programs over an extended period of time. One interesting example is an ongoing research program evaluating GROW, an organization of former psychiatric patients (Rappaport et al., 1985). This longitudinal investigation is most interesting because of its multi-faceted aims and methods (e.g., participant observation and a variety of within-subject and between-subject comparisons are used), and its cooperative nature (the researchers and organizational leaders have compatible goals).

Increasing numbers of reports of experimental studies with stronger designs are appearing in the literature. A recent critical appraisal of health-related social support intervention which adopted a strict methodological approach (Cwikel and Israel, 1988, in press) evaluated evidence from 17 experimental or quasi-experimental studies of social support, all of which incorporated forms of mutual aid with or without professional involvement. Eleven studies reported significant results. The authors conclude that affective support, the use of many

types of support together, and the development of reciprocal ties (all characteristics of most MASH programs) appear to be beneficial and warrant further study.

Research Directions: Gaps and Priorities

All evidence to date suggests that, in general, mutual aid programs have a beneficial impact on the health of many participants and do not cause harm. However, gaps in scientific knowledge about all forms of social support remain, and these same gaps are just as relevant to mutual aid. Identified areas of special concern include:

1. The role of intervening variables: The availability, use and impact of social support are known to be influenced by a number of intra-personal and environmental factors. There are still many unanswered questions about such aspects as the relationship between social competence, personality, coping styles, socio-economic status and other demographic variables.

2. The functions and comparative benefits of natural versus artificially provided social ties and social support: Epidemiological studies have produced findings of significantly higher morbidity and mortality rates in those subjects with less social support and fewer social ties, even after adjusting for health behaviours. However, much more information is needed about whether and in which circumstances social ties lead to new sources of information and support that are demonstrably helpful. Results of a relatively small number of studies suggest that those with low social support may derive the most benefit from mutual aid programs (e.g., Vachon et al., 1980).

3. Development, refinement and comparison of instruments capable of measuring various types of social support: Those interested in studying "main effects" need measures for assessing social networks; those looking at buffering require valid measures of availability and quality. All measures need to examine social support from subjective and objective perspectives.

4. Program evaluation research: The literature discusses the need to evaluate MASH programs on a group-by-group basis since they cannot be viewed as interchangeable components of a system. Methods put forward include summative evaluation, formative evaluation and action research. However, there are few published reports illustrating their application to mutual aid evaluation.

5. Helper therapy: There is certainly some indication that serving as a helper confers additional benefits, but more research is needed before this aspect of mutual aid is fully understood.

6. Experimental research: All experts concur that there is a need for more formal assessments of the influence of mutual aid on health, coping and

adaptation in different contexts. It is not yet possible to differentiate which forms and types of support are most beneficial for particular target groups and conditions. We need to study such factors as optimum level, timing and length of involvement, and to examine a myriad of other intriguing aspects such as the fit between the person and the support offered.

Methodological Considerations

Research into the effectiveness of mutual aid involves some serious methodological difficulties and some insurmountable barriers. Achieving a gold standard is impossible because randomized controlled trials cannot be conducted. Concerns about anonymity and privacy, essential components of some MASH groups, may make the advances of researchers unwelcome. Researchers also run the risk of altering the natural helping process. These groups are usually not motivated to measuring the impact of what they do, and research occupies a very low priority compared to their many other activities. Nor are they interested in keeping systematic records of whom they help, through which activities, and for how much time.

Selection of outcome measures is also difficult due to problems of reliability, validity and generalizability of existing tools. Instruments developed to assess psychotherapy outcome are unsuitable, and the continued development of new groups and approaches makes standardization of tests almost impossible. Large samples are required because so many factors cannot be controlled. Because of the uniqueness of the processes in each group, results concerning the effectiveness of one intervention cannot be generalized to another chapter group of the same overall program, let alone to other programs following the same intervention model. The problems of selecting appropriate comparison groups is another thorny issue. As MASH group members are self-selected, one can never control adequately for sampling biases. That factor alone creates problems in making inferences about for whom a group is helpful and to what degree. It also contributes to error variance (i.e., how a group operates is dependent on its composition).

Although there is general agreement about the need for more research of all kinds (descriptive, hypothesis-generating, hypothesis-testing, program evaluation, etc.), there is much debate and discussion both about what to measure, how, when and for how long, on whom and about the role of the researcher (some believe a new research ethic and a more collaborative stance is indicated, while others disagree). Moreover, some who are connected with the health care system may be threatened by mutual aid initiatives. For example, some clinicians and administrators may view

mutual aid interventions as usurping or compromising their professional authority and domain of power. It is clear that successful mutual aid research demands investigators with a high level of technical evaluative skills who are also sensitive politicians and communicators.

There are, in short, obvious limitations in forcing the evaluation of MASH groups into the classic epidemiological model. However, it is clear that those investigators who are specializing in this field understand the methodological problems very well and are making thoughtful and creative attempts to address them. They have already supplied sufficient proof that appropriate designs *can* be developed and inroads can be made. New researchers investigating the health-related effectiveness of mutual aid need to familiarize themselves with all of the methodological problems and issues. These are described in more detail in our comprehensive review.

Choice of Health Outcome Indicators

When assessing the impact of mutual aid interventions, investigators must begin to pay closer attention to their outcome indices in terms of their reliability, validity, comparability to other studies, relevance to the problem and the population being studied, and generalizability. Assessment of the impact of MASH interventions ideally requires many different kinds of measures—not only those that assess pre/post symptoms but also methods of obtaining data on attributes such as shared ideology and indices of quality of life. A different and broader perspective is advised; investigators are urged to try to tap changes that go beyond but do not exclude traditional physical and psychological health status outcomes. The choice of outcome indices depends highly upon the characteristics of the condition for which mutual aid is supplied, the question being asked and the population under study. Therefore, it is not possible to supply an inclusive list here. However, some indices found to be useful by investigators include:

- Social network attributes
- Amount, sources and types of social support
- Choice, repertoire of coping strategies
- Locus of control
- Optimism
- Goal expectations and attainment
- Anxiety and depressive feelings
- Reduction of stress (appraisal of daily hassles, distress)
- Quality of life, satisfaction
- Sense of mastery
- Reduction of stigma

THE ROLE OF HEALTH AND WELFARE CANADA: RESEARCH AND SOCIAL POLICY

"All scientific knowing is indirect, presumptive, obliquely and incompletely corroborated at best. The language of science is subjective, provincial, approximate, and metaphoric, never the language of reality itself. The best we can hope for are well-edited approximations" (Campbell, cited in Light and Pillemer, 1984, p. 105).

Policy directions are influenced by analyses of both quantitative and qualitative data. Our report concludes that in the field of mutual aid, a number of non-quantifiable social issues must be considered carefully.

Current Policy Issues

In the industrialized world, self-help is not focused on basic survival issues as it tends to be in developing countries. Rather, it has become a growing and increasingly important social and health movement. It is believed to be in part related to public disenchantment with the growing bureaucratization of formal human service organizations, and disappointment with the sometimes limited capacity of the traditional health services to meet their psychosocial and rehabilitative needs. Additional factors include indications of the increasing fiscal and human resources strains exerted on formal systems and the greater social support needs and stresses experienced by more of our citizens. The more recent development of self-help clearinghouses suggests a trend beyond the former emphasis on personal self-change towards coalition building, perhaps in response to funding and programming cutbacks in essential human services.

In the United Kingdom and in European social welfare states, government funding and/or enabling legislation have provided stronger mandates and public support for self-help and informal services. Israel and Australia seem to be moving in the same direction. In the United States, self-help clearinghouses and resource centres now serve over 30 communities and regions. The importance placed on this topic by the U.S. is exemplified by the fact that a top-level policy conference on mutual aid was convened by the Surgeon General in September, 1987. In short, the rapid expansion and obvious signs of popularity of mutual aid programming suggests to policy makers in many countries that they must take this phenomenon seriously.

Since the early 1980s, Health and Welfare Canada has sponsored and supported a number of related individual projects throughout Canada. These include reports on self-help, research studies, program development, directories of pro-

grams, conferences and information for lay persons and professionals. However, despite these many developments, government response in Canada and in many other countries remains tentative and modest. Many social planners, funders and bureaucrats do not yet understand how and where mutual aid should fit into the overall planning picture. The literature reflects the continuing debate: should mutual aid be taken more seriously by health professionals and policy makers as an option that should be available to all, or should expansion of government involvement be discouraged lest mutual aid be exploited as a way to save money on human services? Several authors warn about the danger of social and political misuse of research findings about the benefits of social support. They stress the importance of maintaining an adequate safety net of human services in all communities. Otherwise, families and natural helpers will become strained beyond all capacity and the mutual aid responses will lose their momentum and effectiveness.

Nevertheless, there is general agreement in the literature that methods must be found for incorporating informal helping approaches and mutual aid strategies into planning for human services *without coopting these resources as adjunct services under professional control and without viewing these resources as a cheaper substitute for health and social services*. Some believe that in terms of existing knowledge, it is premature for the government to make large-scale policy shifts. Differences of opinion still exist about what the extent and form of cooperation among government, professionals and MASH programs should be (e.g., should professionals be directly involved with MASH programs? Should these programs be attached to and/or funded by formal services? Should government fund mutual aid programs directly, or only through coordinating mechanisms such as clearinghouses?).

Response to MASH funding and programming by government is highly political. Thus in Canada and elsewhere, mutual aid has tended to play a marginal role in health care systems and reactions of policy makers and planners range from "innocent neglect," to active distrust, to lip-service, to tentative positive steps.

The many complexities of social policy are dealt with in comprehensive detail in the material appended to this short report. Unfortunately, the literature does not provide any definitive answers or recommend simple guidelines for those involved with policy formulation and implementation. Policy makers and planners should be made fully aware of the attractive advantages of social interventions over person-centred interventions in the field of prevention because of their larger impact

and their emphasis on increased personal responsibility. However, it is suggested that more assessment of the implications still needs to take place if development of more sympathetic policies on a grand scale is to be undertaken.

Recommended Directions for Health and Welfare Canada

It is recommended that Health and Welfare Canada adopt a stronger, more definitive position with respect to endorsing mutual aid and furthering related research and programming. Suggested strategies for so doing include:

1. Developing health research and promotion policies that give priority (e.g., through special competitions) to funding research into the health benefits of mutual aid interventions.
2. Adopting a flexible policy of demonstration model program development funding across Canada, that includes direct support on a selective basis both to programs and to coordinating or resource mechanisms such as clearinghouses. Funding decisions should be based on factors related to the problem addressed by the program, the target population, the preferred intervention model and local community or regional circumstances.
3. Assuming a leadership role in educating Canadian policy makers and planners to increase their understanding of mutual aid.
4. Commissioning a national survey that would provide base-line data for planning purposes on the current use and availability of mutual aid programming in Canada.
5. Collecting and disseminating information about the health applications of mutual aid, particularly to those in the health professions and in health and social service organizations.
6. Promoting the education and training of health and social service professionals, to increase their knowledge and skills in research, program development and consultation with respect to the health applications and uses of mutual aid, by sponsoring workshops and conferences. These events should be designed so as to create opportunities for increased collaboration among those from various specialties and disciplines.
7. Fostering development of federal public policies that promote mutual aid strategies and that recognize the interdependence of mutual aid with all of the elements of the "Health Promotion Framework" document. For example, strategies for creating healthy environments should deliberately build in opportunities for the expression of mutual aid in the planning process and the solutions. Conversely, mutual aid vehicles could be used to inform and guide people towards practising better self-care and creating safer environments.

CONCLUDING COMMENTARY

Ideally, future policies should reflect the federal government's heightened awareness of the crucial importance of social support and social networks to all Canadians. The evidence is becoming more convincing that the association between social support and social ties and physical well-being is not simply reflective of better risk profiles or health practices, but rather represents an influence on host resistance to disease. Seeman and Syme (1987) observe that "man has evolved as a social animal because living in a group conveyed survival

advantages"; they go on to assert that the evidence is becoming increasingly strong that being supported and cared about may confer both physiological *and* psychological survival advantages.

This report provides many examples of how mutual aid programs can serve as powerful and constructive methods for people to help each other and themselves. Furthermore, it recommends that as the full potential of this mechanism for prevention of disease and health promotion appears to be untapped in Canada, Health and Welfare Canada should take a leading role in the careful fostering of this important human resource.

HEALTHY ENVIRONMENTS FOR CANADIANS*

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*** Summary version**

HIGHLIGHTS

- The knowledge that physical and social environments have an important effect on the health and well-being of Canadians has not been widely applied in Canada's health care delivery systems, in the design of other social programs and institutions, or in the design of physical settings.
 - The greatest immediate health benefit could be derived from the creation of building designs, operational procedures, building and maintenance materials, and other products that do not lead to polluted indoor air.
 - If healthy environments are to be achieved for all Canadians, we must:
 - value each person, regardless of age, gender, family type, race, culture, illness, sexual orientation or lifestyle. Achieving equal status for women is of particular importance;
 - ensure that our common environments are accessible to all, and that our specialized environments are not only physically accessible, but psychologically and socially healthy as well; and
 - involve at the design stage those people who will be affected by a physical setting, social program or institution.
 - The scientific basis on which to proceed with design of healthier environments must include research and development of emerging technologies which gives detailed, quantified information on the effects of different environments on health.
 - Other action required includes:
 - educating the public about the effects of environment on health, and on means of creating healthy environments; and
 - reviewing current legislation to determine the extent to which individuals have control over their environments.
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INTRODUCTION

Physical and social environments have an important effect on the health and well-being of people in Canada. Although this connection has been known and documented for many years, the knowledge does not appear to have been widely applied within Canada's health care delivery systems and in the design of physical settings and social programs and institutions in Canada.

There are major health and safety issues to be addressed in virtually every physical setting in Canada—in homes, in schools, in the workplace and in public places, including the natural environment. Creating building designs, operational procedures, building and maintenance materials and other products that do not lead to polluted indoor air is a common priority in all settings, and one that would appear to lead to the greatest immediate health benefit.

Many people in Canada are stuck in physical settings and social conditions which are unhealthy for them. Poverty and unemployment, for example, are major contributors to ill health. In many cases, either overt or subtle forms of discrimination (devaluing of one group of people by another) are involved in confining an individual to unhealthy environments. Prejudices based on age, gender, family type, race and culture, illness or handicap, and orientation and lifestyle are common in Canada. If healthy environments are to be available for everyone in Canada, we must begin on every level to treat each person, no matter what their characteristics, as a person of value. In particular, achieving equal status for women in Canada is essential.

Many of our common environments ignore the true range of physical and cultural differences among people in Canada, and are less accessible than they could be. Some of our specialized environments recognize our physical differences, but forget the rest of our human characteristics and needs. They may be safe, or accessible, yet psychologically or socially unhealthy. A new vision of environmental choice and greater individual control over environment is needed.

Creating better environmental designs, eliminating personal and structural prejudices, and applying new knowledge about environmental health within Canada's health care systems, all require a much more detailed understanding of the true diversity of Canada's people, their social and psychological characteristics, their needs and goals, and their physical differences in vulnerability to different environmental stressors. Direct participation of individuals who will be affected by any physical design, social program, or social institution is required.

Research and development of emerging technologies which give detailed, quantified information on the

effects of different environments on health will provide the scientific basis on which to proceed to design healthier environments in Canada. Creating healthy environments in Canada, and producing a new generation of safer, cleaner materials and products will enhance Canada's industrial and scientific reputation, and distinguish Canada's products and services from those of other countries in world markets.

SYNTHESIS OF THE LITERATURE REVIEW

The following is a brief synthesis of the major conclusions arising from the literature and from ideas obtained by research contacts. A detailed analysis of research and other information on healthy environments is presented in the full report under "Part II: Analysis."

a) Our physical environment can affect our health

Dangers in the physical environment contribute significantly to the risk of injury, ill health, or death, for many people in Canada. The physical environment contains some health or safety risks in virtually every Canadian setting: homes, schools, workplaces, and public environments, including natural environments.

b) Indoor air pollution is a significant component of the risk

The contamination of indoor air by numerous chemical emissions represents a significant component of the overall risk to health posed by physical environmental factors. Indoor emission sources include industrial processes, building materials, furnishings, combustion devices, maintenance products, pest control substances, personal care or pleasure products and human metabolism.

c) Pollutants in food, water, and outdoor air are also stressors

Trace-level contamination of food, drinking water and outdoor air, with a wide array of pollutants of varying toxicities, likewise presents a general chemical stress to which virtually everyone in Canada must adapt.

d) Social and economic conditions can definitely affect health

Unemployment, poverty and financial stress, work pressures, family problems, prejudice and oppression, isolation, and lack of control over one's life are all examples of socio-economic conditions which can have an adverse effect on physical and mental health. Conditions previously thought of as merely unfortunate (at least by the fortunate) can

be highly stressful and clearly have more health cost than has been commonly acknowledged.

e) There is a wide range of vulnerability in the population

Each individual is unique in his or her reactivity to physical environmental factors. The population contains a wide variety of people, ranging from those who can go about their lives with little or no effect from their immediate physical environment, to individuals who are severely impaired in their day-to-day functioning by one or more specific environmental factors. Any one individual may have a unique array of sensitivities—he or she may be quite insensitive to one factor while being sensitive to another.

f) Limits to adaptation to changing environmental conditions

Some people appear to be suffering, at least temporarily, from an inability to adapt to changing conditions, particularly increased pollution load. A healthy environment and lifestyle appears to be one in which an individual has sufficient control to limit the amount of adaptation required at any one time, and to shape the environment to accommodate his or her inherent nature, rather than the other way around.

g) Environmental health issues are different for each of us

Environmental health issues vary widely according to different human characteristics and situations. People of different ages, gender, family or household types, races or culture, health status or mobility, sexual orientation and lifestyle all encounter variations of general environmental health issues, which are unique to their situation. Each different physical setting and each different social and economic condition brings with it new viewpoints and priorities in environmental health. Understanding this diversity of issues is an important key to achieving health for all.

h) The paradox in environmental design

Many environments (e.g. public spaces, offices, schools) do not accommodate well the full range of human characteristics. People who are handicapped, less mobile or chemically hypersensitive, for example, have been lumped in the category of "special needs" and often excluded from consideration, even though making environments accessible to them might also benefit the rest of the population, both physically, by many of the health and safety features required, and socially, by their presence. Where special environments have been created, they accommodate well certain unique needs of such individuals, but often ignore the rest

of their human characteristics and isolate them from others.

i) Social conditions and being devalued trap people in unhealthy environments

Many people in Canada become locked into situations where they are exposed to unhealthy environments. Certain groups are subject to environmental hazards more than others. Devaluing or undervaluing certain groups of people (e.g. women, blue collar workers, handicapped people) can lead to widespread disparities in both social and physical environmental conditions.

j) Prejudice is itself unhealthy

It is now clear that victims of prejudice and oppression suffer the direct physical and emotional health effects of such an unhealthy social atmosphere, in addition to the indirect environmental consequences arising from the discrimination they experience. The "inferiorized" often internalize some of the attitudes toward them and can be subject to a spiral of decreasing self-esteem and the many other problems that develop from that. Many people are undervalued ostensibly because of one characteristic for which they are singled out, which is bad enough, but the nature of prejudice is such that the rest of their human qualities are also rejected in the process.

k) Social and personal support is important

The extent of an individual's personal and social support network is an important determinant of health. Isolation increases health risk and also guarantees that a person's needs and value, remain invisible to others.

l) More personal control and participation can reduce hazards

Many people in Canada voice a hopelessness about reducing their health risks from environmental exposures because they lack sufficient control over their personal and social surroundings to effect the changes they want. Participation of the people of Canada in the creation or modification of their physical and social surroundings is a feasible and important step in creating healthier environments. It is critical to introduce into the design process sufficiently detailed information about the full diversity of the people being served. A great deal of knowledge is already available about user participation and need only be implemented.

m) New ways of measuring effects of environment change our views

Advances in measuring pollutants and the ways we are affected by them are revolutionizing the

field of environmental health. Health and performance effects are becoming apparent at levels of exposure previously considered safe, and questions are being posed about the unknown and possibly synergistic effects of mixtures of trace levels of pollutants. Emerging new technologies provide the basis for scientific selection of healthier environments.

GAPS IN KNOWLEDGE

It would be much easier to determine which environments are healthy and which are not if a number of gaps in our knowledge base were filled. These include:

a) Detailed health effects on individuals

With few exceptions, we do not know the actual effects of many environments on individual human beings. Much of the research designed to help decide what is healthy and what is not is of an epidemiological or other statistical nature, or involves the effects of environment on animals rather than humans. While helpful in determining general environmental standards and identifying major hazards, this level of detail is not sufficient to make truly competent decisions about healthy environments for specific individual human beings which, after all, is the basic question each individual in Canada faces, and one that health care professionals must also deal with. Imagine a time when each person in Canada could have a profile of his or her individual adaptability to different kinds of environments.

b) Population profiles of environmental sensitivities

We do not know at the moment, with any degree of accuracy, how sensitivity to environmental insults, either physical or social, varies across the population. Without this we cannot make competent decisions about design standards for physical, social, or economic environments in Canada. One profile urgently needed is that of people's degree of reactivity to common mixtures of indoor air pollution.

c) Profiles of the extent of diversity in Canada

A true picture of the extent of diversity of human characteristics and situations among people in Canada has yet to be painted. Statistics are currently gathered under certain basic characteristics (e.g., gender, marital status, age, diseases, income, education, employment, etc.) and are usually ana-

lyzed separately. But each individual has many diverse characteristics, and a richer picture of these characteristics and their various combinations is more useful for physical, social, and economic design decisions. Categorizing people by single characteristics pulls us toward thinking about stereotypes rather than about accurate descriptions of people. How many young, black single women with an interest in learning more about computers are there in Canada, and how can we help them create a healthy environment for themselves? How would our approach differ if we knew more about them?

d) How physical, chemical and social stress affects our bodies and minds

We lack detailed and verified knowledge of the mechanisms by which various stresses adversely affect human health. For example, it is known that low-level chemical exposures can trigger many measurable symptoms in sensitive individuals. There is no consensus on the mechanism by which such individuals are affected. Immunology research is teaching us that many body parameters are affected by stress of all kinds, but more work is needed to unravel the remaining details.

e) How to help heal the victims of environmental stress

There is limited experience in helping individuals to heal the adverse effects of their environment. Clinical work is being done with people who become hypersensitive to minute chemical exposures, but there is no consensus yet on appropriate therapy, other than reducing the stress load on the individual. This is a serious gap in light of the fact that many physical and social factors in present-day Canadian environments pose considerable health risks.

f) Knowledge of the effects of cleaner environments

We are no longer in the position, in Canada, of having comparison populations who can give us a clear picture of what health could be in a much less polluted and much less stressful environment. Most people in Canada are exposed to complex mixtures of indoor and outdoor contaminants, albeit at trace levels. While lifestyles vary considerably, most Canadians also experience a complex environment of social and economic stress. Competent decisions about the value of less polluted or less stressful environments will require good information about the effects of alternatives. To gather this knowledge, experimental situations will be required.

METHODOLOGICAL CONSIDERATIONS

Much of what is needed in the field of environmental health will involve the extension of technology and research methods well beyond the present state-of-the-art. It will involve tackling physical and social stressors without an overlay of hopelessness which presumes, without testing the limits of our ingenuity, that nothing can be done. Some examples of new methodologies needed are as follows:

a) Protocols for measuring chemical hazards

It has become important to know, in far more detail than before, how products behave, physically and chemically. We require efficient and economical laboratory protocols for determining what substances are given off into our air and onto our skins, by the materials we handle and the environments in which we live.

b) Protocols for measuring effects of environment

We need well-controlled, scientifically-verified procedures for obtaining accurate answers about the effects of specific environmental exposures on individuals. New and promising technology, such as computerized brainwave analysis and other developments described in this review, may provide the means of doing this.

c) Protocols for responding to physical environmental complaints

We need better protocols for responding to situations in which individuals feel that their immediate environment is making them ill. While industrial situations involving high-level exposures have been well addressed, situations where exposure levels are below accepted standards often are not satisfactorily resolved. These will require better detective work, a greater understanding of the possible effect of low level exposures on sensitive individuals, and more direct involvement of people who are affected.

d) Protocols for measuring the effects of alternative environments

New procedures, facilities and technology are needed to open up a new field which might best be described by the term "experimental environmental health". Sometimes the best way of determining the effect of an environmental stressor is to remove it from the environment, and to measure how we feel about it. This would open the way to using individuals as their own scientific controls,

and, in combination with protocols for measuring the direct effects of environmental stressors, determining the precise role of a particular stressor on an individual's health and well-being.

e) A means of interrupting prejudice and oppression

For years, we have relied on the idea that prejudice in Canada will naturally decline with each new generation. Legislation has been used to guard against blatant violations of rights, and some focus has also been placed on acknowledging and welcoming multiculturalism in Canada. What has yet to be done well is research to determine how we can deliberately reverse existing prejudices and eliminate oppressive institutional practices in a much shorter time frame. The key to doing so is making far more information available about the full human nature of devalued individuals.

f) Methods for population-wide education about environmental health

Environment plays a far bigger role in health than has been previously accepted. Many people in Canada are both adversely affected by environment, and ignorant of the possibility that environmental factors may be contributing to their ill health. Those they consult about health often overlook environment as a factor. Since achieving healthy environments is a very individual affair, health for all cannot be achieved without widespread knowledge of the role of environment in health. Effective ways of spreading this knowledge must be chosen, tested, evaluated and implemented, if health for all is to be achieved.

g) Methods for allowing greater individual environmental control

Both physically and socially, Canadians have a better chance of maintaining their health and thriving if they have control over their lives. Alternate living conditions, location, employment, education and lifestyles are not available to those who are locked in by lack of resources or by other oppressions that restrict their life choices. We need a more creative effort at every level (from building design to design of all our social and economic institutions) to allow individual diversity and control.

h) Greater participation by individuals in physical and social design

A great deal of work has already been done on user participation in design. Methods appropriate to each new design situation need to be selected from the literature and put into practice.

SUGGESTED INDICATORS

Canadian society is rich with indicators of environmental problems, in the form of specific physical health, mental health, and social problems that could be the result of unhealthy environments. At our present state of knowledge, however, it is difficult to link cause and effect. Enough practical experience has nonetheless been gained to guide the way in searching for environmental conditions which can and should be changed. Currently, we are often focusing solely on the indicator as a problem or disease in itself.

The first line of defence for understanding the connections between unhealthy environments and the effects, and therefore for finding reliability indicators, is *direct contact* with people who are ex-

periencing ill health. In our zeal for obtaining objective and measurable indicators in the past, we have often ignored subjective information that provides clues which are both useful and necessary to carrying on the detective process. Once those clues have been processed and understood, there is an important role for scientifically-determined indicators. The process requires both.

There are many problems in Canada that could have environmental factors as possible contributing causes. Rigorous investigation of these possible connections, including direct contact with individuals affected will yield indicators that can be used with better confidence. Some possible health indicators are listed below along with the environmental connections suggested in the literature:

<i>Environmental condition</i>	<i>Possible indicators</i>
indoor air pollution	unexplained physical illness frequent medicinal drug use learning disabilities
outdoor air pollution	hospital admissions for respiratory illness mortality from respiratory and cardiovascular distress
contaminants in food and water	cancer incidence allergic reactions
sexism and oppression of women	female/male income disparity poverty among women sexual harassment and assault battering of women
adultism	apathy among young people drug and alcohol abuse sexual and other child abuse youth suicide rate
unemployment	physical and mental illness poverty
prejudice	under-representation of groups in employment, education and economic categories invisibility or closeting of certain characteristics
job stress	substance abuse mental health admissions unexplained physical illness
restricted information	unwanted pregnancy sexually transmitted diseases mortality from AIDS
undervaluing elderly or handicapped people	fear of aging loss of self-esteem inadequate health care poverty

For each type of environmental stressor, specific indicators are needed to signal potential problem levels, recognizing that this method will only alert us to the levels at which relatively large numbers of people may begin to be adversely affected, and will not be sufficient to warn of damage to those who are more sensitive than most to each factor.

For indoor air pollution, residential exposure guidelines have been developed and are being refined by a joint Federal/Provincial Advisory Committee on Environmental and Occupational Health. These guidelines contain some consideration for sensitive individuals. Environment Canada guidelines on outdoor pollutants provide some measure of problem levels, but do not yet address the problem of the more sensitive individuals.

Direct behaviour indicators for measuring our progress in reducing attitudes and actions which devalue other people have yet to be systematically researched, refined and applied. We have not used a "sexism scale", for example, to chart our progress in eliminating the oppression and undervaluing of women in Canada. Nor have we used a "racism scale" or "anti-gay scale" to measure the extent of prejudice that is still targeted against individual human beings who happen to have, among their diverse characteristics, specific origins, skin colour, sexual orientation, or family lifestyle that have been judged by others as undesirable, based on stereotypes.

We also need performance indicators, calibrated in clean, healthy environments, to be able to measure impairment of human beings due to environmental factors. The more ubiquitous the chemical contamination, the less we can call on present baselines as "normal" performance.

DATA NEEDS

It is sometimes appropriate to focus our full capabilities on a problem even if only a few people are affected (e.g. arranging a liver transplant for an ailing infant). However, the nature of the resources we allocate often depends on the magnitude of each problem we face.

We therefore need to know the number of people adversely affected by specific environments. For example, we need to know the number of children whose health and learning are actually now being impaired by indoor pollution in the schools. We need to know the number of industrial workers whose well-being has already been eroded by industrial chemical exposures. We need to know the number of women who are battered, the number of children who are abused, the number of people who are discriminated against, and so on.

Each area of study suggested in the previous sections will require its own type of data. Determining the list of "numbers needed", however, is more appropriately left until basic, qualitative information about the problems we have discussed has been gathered and understood in the context of healthy environments. In this literature review, we do not pretend to have investigated environmental health problems in sufficient detail to be more specific about data needs.

The next step after initial awareness of environmental health problems is more direct contact with individuals who have been affected. Even a count of the number of people who come forward with information, once invited, will be helpful in determining the minimum order of magnitude of each problem. The understanding gained from direct contact will help to determine exactly what, or who, should be counted.

PRIORITY QUESTIONS FOR RESEARCH

General research needs have been described in the foregoing sections and in the full report under "Part II: Analysis". The following list places priority on certain subject areas over others.

a) Experimental environmental health and treatment of environmental illness:

establishment of a field of research in which human beings are observed in alternative, cleaner, less stressful environments, and in which effective treatments are developed for people who are adversely affected by physical and social stressors.

b) Pollution, health and performance:

development of measurement devices and protocols for determining both obvious and subtle health and performance effects in individuals exposed to pollutants.

c) Elimination of prejudice:

development of practical ways of eliminating prejudice and discriminatory behaviour, individually and collectively.

d) Adaptable physical design:

continued development of physical designs (e.g., buildings, public spaces) that accommodate a wider range of diversity.

e) Health monitoring devices:

development of devices that can be used by individuals at home, at school, or at work for monitoring both environmental and health conditions.

f) Specific hazard investigations:

further detailed investigation of newly recognized health hazards (e.g. airborne mycotoxins from household mould growth, and mixes of volatile organic chemicals) in home and work environments.

g) Safe product research:

promotion of the design of safer, less-polluting products of all kinds, with priority given to building materials and interior finishings such as paints and household combustion devices.

h) Social environment research:

investigation in more detail of the effects of various social environments on health.

i) Internalized oppression.

development of practical ways of addressing the effects of oppression in individuals who have been undervalued, and of encouraging their full powers and capabilities.

j) Alternative social structures.

investigation of alternative income systems, social structures, institutions and legislation which will promote a society where all people with minority characteristics are fully valued as human beings, and not merely tolerated.

k) Healthy lifestyles:

investigation of alternative lifestyles or lifestyle factors which will contribute to better physical and mental health.

POLITICAL AND SOCIAL CONSIDERATIONS

Sufficient new knowledge has accumulated over the last few years concerning the connection between environmental factors and ill health to have caused increased pressure on politicians, governments, organizations, employers, physicians, and health care institutions to provide or promote healthier environments in Canada.

Some of the important new political and social considerations arising from the present review appear below.

a) "Health for All" requires elimination of prejudice

One inescapable conclusion of the literature is that environments of prejudice and oppression contribute to ill health in many ways, both destroying self-esteem and locking some individuals into situations where they have less control than others over income, lifestyle and surroundings, and hence their

own health. The government cannot pretend to work toward "Health for All" without taking an active role in achieving the complete elimination of various kinds of prejudice and oppression presently operative in Canada, including:

- sexism (oppression of women by men)
- ageism (devaluing of elderly people by younger people)
- adultism (devaluing of younger people by adults)
- racism (devaluing of one race or ethnic origin by another)
- prejudice against one religion by another
- gay oppression (prejudice on the basis of sexual orientation)
- devaluing of people who are unemployed
- devaluing of people in less advantaged economic positions
- devaluing of people who are handicapped
- devaluing of people who are physically or mentally ill

b) Healthy environments require individual freedom and control

If Canada is to move towards healthier environments for all, we must move in the direction of greater control by each person over his or her own surroundings and lifestyle. This has implications for building design, housing, income distribution, employment policy, income alternatives, human rights, health systems, pollution standards, and many other areas. The vision is one of *environmental choice*, respecting the vast diversity of human characteristics and situations in Canada. It leads to more individual empowerment, more diversity and, ultimately, to healthier and more effective human resources in Canada.

c) Structural, legislative and attitudinal changes may be required

In many ways, Canadian society from top to bottom has been paralyzed with a kind of hopelessness that says certain things can never be changed. In pollution control, in environmental design, in health care, and in social programs, the focus has been on meeting standards which accommodate the bulk of the population. The hidden assumption is that we cannot accommodate everyone. "Health for All" contradicts this notion and suggests that we need flexible, clever designs in our physical environments and in our social structures, that will accommodate everyone well.

The literature did not reveal any real barriers to achieving this. It did suggest, however, that achieving healthy environments for everyone will require not only physical changes, but legislative, struc-

tural, and attitudinal change throughout our society's major institutions as well.

d) Participation must be welcomed

Environments will be healthier when those who are affected by them participate in their design and in their ongoing maintenance and development. This applies to legislative and social program design as well as to physical design. Many methods for user participation have already been developed and need only be selected and applied.

e) There is a worldwide market for expertise in healthy environments

Because of the obvious advantages for the health of people in Canada, a focus on making environments healthier will inevitably lead to economic spin-offs and exportable expertise of products and services. Becoming world leaders in the design and production of safe, non-polluting products and clean, healthy, supportive environments would be consistent with Canada's present world image as a clean, healthy, and peaceful country.

IMPLICATIONS FOR ACTION

There are four major areas of action that arise out of a commitment to seeing that healthy environments are available to everyone in Canada.

a) Political vision and leadership

A new public stance at the highest level is needed to provide leadership in bringing about healthy environments, and to share the following visions:

- environment is important in the health of Canadians;
- diversity is welcomed and valued in Canada;
- individuals deserve to control their own environments;
- prejudice and discriminatory behaviour in Canada must end;
- Canada can become a world leader in environmental health.

b) Scientific and social research, and Industrial Incentive

Technologies and methodologies which allow better understanding of the effects of both physical and social environments on health need to be developed and supported. Industries need to be aware that Canadians want and demand cleaner, less damaging and less risky products and materials. They may require some research support to do this product development well. Assistance in promoting clean, safe Canadian products in world markets might also be offered.

c) Public education

We need much more detailed and widespread education about the effects of environment on health, and on ways of creating healthy environments for everyone. We also need to create a better understanding of the fact that there is a wide range of vulnerability to environmental stressors among the population. It is important that this range not be used as a basis for prejudice by people in one part of the range, towards people in the other.

d) Legislation

Existing legislative powers need review to determine the extent to which every person in Canada has adequate control over his or her own personal environment. Health and safety legislation for neglected settings and groups (e.g., for schools and tenants) needs to be encouraged at the appropriate government level. Any aspect of existing legislation, regulations, or institutions that may inadvertently devalue or restrict the opportunities of any Canadians on the basis of their inherent characteristics or situations requires critical review, with participation by the persons who are affected.

As an initial focus, a complete re-examination of the ways in which sexism is institutionalized should be undertaken, and proposals should be prepared for accelerating the timetable for achieving full equality for women in Canada.

5. THE IMPLEMENTATION STRATEGIES

As a response to the health challenges identified in the Health Promotion Framework, three strategies provide a starting point for action aimed at achieving health for all Canadians. They are:

- fostering public participation
- strengthening community health services
- coordinating healthy public policy.

The notion of empowerment underlies all the concepts presented in the Health Promotion Framework. It is the consumers of health programs and services who know what their own health needs are and how they can best be met; taken as a whole, the framework strategies provide direction for our efforts to ensure that people play an active, central role in health promotion.

Fostering public participation is the strategy that provides the clearest opportunity for people to be involved in decisions affecting their own health. It reminds us that the ultimate aim of achieving health for all cannot be attained unless we promote and support involvement at the most basic levels in families, neighbourhoods, and communities. This strategy calls for a redistribution of responsibility among key players in health, including policy-makers, professionals and consumers of health services, and a corresponding redefinition of roles and functions. Communities, "have-not" citizens, and legitimate interest groups must be included in determining how resources are allocated, how information is shared and how policies are set. Finding effective ways to do these things must be a principal research objective. This strategy offers extensive scope for investigation and action of many kinds.

Both of the research papers dealing with fostering public participation stress the need for a clearer understanding of what public participation actually is. David Zakus and John Hastings consider that participation is a fundamental right and a means for achieving societal goals. Mary Powell invites us to consider the social and political implications of encouraging public participation.

Communities where people live and work are the most important setting for action on health. *Strengthening community health services* means ensuring that a flexible continuum of support is available, whether temporary or long-term, to enable people to meet their needs for assistance without disruptive and disorienting moves and without institutionalization, unless this is absolutely necessary. Such services should be tailored to the particular needs of the community, and expressly oriented towards promoting health and preventing disease. This calls for local-level research

and action. Indeed, Aldred Neufeldt's review of the literature on community health services points to the need for considerable research and action aimed at determining the optimal mix of community supports and services, and the most appropriate allocation of financial and human resources.

The strategy of *coordinating healthy public policy* offers an opportunity to maximize the potential of all the individual elements of the framework. Coordination requires a common vision, cooperation and collaboration across sectors and jurisdictions, and the establishment of structures that make this possible. In the words of the framework document: "The concept of boundaries is inappropriate when we speak of the promotion of health." In reviewing the literature on this relatively new field of implementing healthy public policy, a team of researchers from the Department of Behavioural Science at the University of Toronto borrow and adapt concepts from the better-established field of planning.

The three strategies work best when they are synchronized. Community health services are automatically strengthened by public participation and by the existence of a strong set of public policies that are coordinated at the local and national levels. The linkages between the strategies and the other elements of the framework require considerable investigation and there are many questions to be answered. How, for example, do community health services foster self-care, mutual aid and the creation of healthy environments? What is their role in enhancing coping? What can we do about fragmented public policies that undermine prevention efforts? What is the meaning of public participation for disadvantaged groups in our society? How is it relevant to the challenge of reducing inequities?

One imperative that cuts across all of the challenges, mechanisms and strategies is the need to combine action and research. Douglas Angus of the Institute for Health Care Facilities of the Future examines experiences in combining action and research from the perspective of a rational planning model. This paper consolidates many of the issues raised in the other reviews, and Angus identifies certain broad areas to be considered before research is undertaken on specific cells of the framework. This "cross-cutting" paper, together with Carol Buck's paper on methodological issues in the study of health promotion programs, have been placed for convenience under the *Implementation Strategies* heading.

FOSTERING PUBLIC PARTICIPATION

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HIGHLIGHTS

- The current literature on public participation:
 - does not provide us with an accurate picture of how public participation takes place in Canada, either in health or in other fields, nor does it offer a reasonable inventory of existing participatory approaches or mechanisms.
 - reflects a narrow view of public participation (i.e., collective citizen action directed at influencing government decision making) rather than the broader definition (i.e., the individual and collective action of people to become involved in and improve their community).
 - is not a unified body of theory and research. The greater part of it is non-empirical in nature reflecting the lack of a broadly-accepted research agenda in this field.
 - Research and action in the following areas would be useful:
 - development of a clear picture of what public participation is and why it has been identified as desirable;
 - examination of the goals for public participation, in light of actual experience with participation;
 - empirical research into the similarities of and differences between self-care, self-help/mutual aid and public participation, in order to develop strategies to encourage these three activities; and
 - investigation of the role and effectiveness of participation in existing health structures, mechanisms and organizations.
 - Further exploration and development of the Health Promotion Framework by a multi-disciplinary group of researchers and practitioners is strongly recommended. Research priorities for the Framework as a whole should be developed.
 - The social and political implications of encouraging public participation, and more generally, of encouraging health for all, must be recognized and considered.
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INTRODUCTION

What do we mean by public participation? And what implications does it have for health promotion? The federal government's Framework for Health Promotion identifies "fostering public participation" as one of the implementation strategies to be used in meeting the aim of health for all. A survey of the literature leads us to the fundamental problem of defining this well-intentioned strategy. Interpretations differ, and the vast majority of the sources surveyed deal with only one narrow—albeit important—area of participation. Therefore, in exploring public participation and identifying research priorities, our first task is to develop a concept of public participation that encompasses a broad range of interpretations.

Our working definition is that *public participation means the individual and collective action of people to become involved in and improve their community*. There are three points worth noting. First, we have included both individual and collective action because we want to take in a wide range of possibilities—from the simple, altruistic action of an individual who gives blood, to more involved collective actions such as forming a group to try to get a community health centre started. Second, we have used the term "of people" to emphasize that the participants are not necessarily citizens or health care consumers, but are simply members of the general public. Third, we have specifically mentioned involvement (as well as improvement) to make the point that we want a socially-engaged or socially-involved public, and that participation should be encouraged for its own sake as well as for what it can accomplish in the way of community betterment.

Although our working definition includes both individual and collective action, we are focusing on collective action in this report because we are trying to illuminate the heart of public participation. Once this has been done, it would be very useful to explore the boundaries between public participation, self-help/mutual aid, and self-care; or, to put it another way, to investigate the relationship between individual and collective action. We hope that this report, along with the reports from the self-care and mutual aid projects, will form the basis for that second-stage investigation.

In exploring public participation, as defined above, we suggest that participatory actions are generally directed at three goals: first, some actions are intended for purely social or recreational ends (e.g., involvement in community sports leagues); second, some actions are primarily directed at individual, community, or group betterment (e.g., involvement in the programs of United Way agencies); third, some actions are mainly designed to influence government decision-making (e.g., involvement in urban planning advisory committees). In practice, the three categories often overlap.

The literature of "citizen participation"¹ deals almost exclusively with actions in the third category. In other words, *citizen participation means collective citizen action directed at influencing government decision-making*. There are two main reasons why the literature takes this focus. First, during the 1960s and 1970s, when the contemporary concept of citizen participation emerged, much of the struggle for participation centred on urban renewal and land-use decisions. In these areas, the key decisions were made by governments (usually at the municipal or regional level), and the purpose of participation was to influence these decisions. Second, citizen participation was justified by the argument that citizens have a right to have a say in the decisions that affect their lives. This was an essentially political claim that arose out of citizens' alienation from and disaffection with government decision-making and one that drew its legitimacy from democratic theory.

In the discussion that follows, we use the term "public participation" in the broad sense given by our working definition, and the term "citizen participation" in the narrow sense used in the literature. It is important to emphasize that the literature reported here deals with only one part of what we consider public participation. In discussing the gaps in knowledge, we are pointing out not only weaknesses in the citizen participation literature, but also gaps between the narrow confines of citizen participation and the broader subject of public participation. This has important implications; in particular, it means that some of our ideas do not emerge directly out of the literature we reviewed. Rather, they are based on our knowledge of, and practical experience with, participation and on our view of what a wider body of literature would or could discuss.

SYNTHESIS OF LITERATURE REVIEW

We reviewed literature on citizen participation from both Canadian and American sources, mainly in English but with some French-language items included. The Canadian material included both scholarly articles and items from the more popular literature. American material was limited to scholarly works. The initial bibliography was generated through a combination of computer and

1. The term "public participation" has generally not been used as a subject heading by cataloguers or compilers, and in either computer or manual searches, it produces relatively few entries. It does occur in document titles, but such documents are almost always identified as belonging to the subject category "citizen participation".

manual searches, using the National Research Council's CAN/OLE System, Telecom Canada's iNet 2000 System, and the reference collection of the National Library. The key words were citizen participation,² public participation, citizen involvement, citizen action, social participation, political participation, community action, community development, and voluntary action. From the original lists, we have prepared an annotated bibliography of 205 sources (182 English and 23 French). This is included in our full report.

We have classified the literature on citizen participation as follows:

- I. Empirical (20%)
- II. Non-Empirical (80%)
 - A. Descriptive
 - B. How participation can be improved
 - C. Why there is not more, or more effective, participation
 - D. Contributions to theory

The fact that most of the literature is non-empirical is an important finding, and reflects the lack of an accepted research agenda in this field. In fact, there is an imbalance between the theory and practice of citizen participation. On the one hand, there is a well-developed body of democratic theory and a sizeable literature that looks at the relationship between participation and democratic theory. But the current, pragmatic interest in citizen participation is only very loosely related to that literature. In practice, because citizen participation has arisen out of citizen discontent with government decisions, it tends to be examined in the context of particular decisions in the areas of environmental regulation or health planning or urban renewal. As a result, citizen participation is not situated within a particular discipline. Specialists from a variety of fields, including political science, sociology, social work, and urban planning have demonstrated an interest in the subject, but none has succeeded in setting out concepts or a research framework that have received general acceptance.

At the same time, because it is a current and practical concern, citizen participation has received considerable attention from non-academic writers. Their contributions have been pragmatic, but they have rarely furthered the debate about how to define citizen participation or how to explore the concept systematically. On the whole,

2. We did try some key words in French (such as "participation citoyens"), but this was not as effective a search strategy as using English key words and then specifying that we wanted French-language items.

then, the literature is not a unified body of theory and research.

I. Empirical

Of 205 items, roughly 20% can be classified as empirical; that is, they deal with an actual experience of participation (or lack of participation). The empirical literature is of two types. The first and more common is the report of a case study, in which a participation experience is described and analysed. The participation reported in these case studies took place in a wide variety of areas, ranging from library planning to health to nuclear power, but the most frequently reported areas were urban planning and environmental/resource management. The second type reports on quantitative research about citizen participation, often based on surveys of citizens' associations or of agencies in which citizens participated. Much of this research was done in the United States following passage of legislation requiring "maximum feasible participation" and is concerned with assessing the effects of such legislation.

The strength of the case studies is that they provide considerable detail and a good picture of what actually happened, but it is seldom clear how the case extends or deepens our knowledge of participation in general. At the same time, however, there is a considerable convergence between the findings of these case studies and the issues raised in the non-empirical literature, particularly in the items that address how to improve participation and why there is not more, or more effective, participation. The case studies document modest practical successes, but also point to the importance of institutional barriers, the problems of involving a cross-section of the community, and recurring conflict between professionals and lay participants.

The quantitative research does try to address general questions but most studies define participation so narrowly or so formally that it is not clear what what they are measuring really is participation. Much of this literature has emerged from the American experience during the 1970s with "maximum feasible participation." As a result, it deals with a very specific institutional and legislative context, and its applications may be limited.

II. Non-Empirical

The majority of items on citizen participation fall into the non-empirical category; that is, they do not report on any actual experience of or research into participation. Usually, they discuss citizen participation from some viewpoint, relying on the authors' own knowledge and beliefs about the subject. This part of the literature can be subdivided into four categories.

A. Descriptive: Many of the books and articles deal with what citizen participation is, how it arose, and how it takes place. The authors share the common beliefs that citizen participation is desirable and should be encouraged, that it takes many different forms, that it should not be restricted to a particular stratum of society or mechanism of participation, and that effective participation involves a continuing struggle to overcome a wide variety of obstacles, both intended and unintended.

B. How participation can be improved: Items in this category focus on overcoming obstacles to participation. The authors share a belief that obstacles *can* be overcome, and that there are no really fundamental barriers to participation. Articles of this type are concerned mainly with the means of achieving participation and its technical elements: do advisory councils work? should participation in public hearings be funded? how can we get technical information to participants? how can we encourage governments to be genuinely open to citizens' views?

C. Why there is not more, or more effective, participation: The authors in this category are less sanguine about participation than those in A and B, and more critical in their perspective. Their common starting point is that participation is a good thing but that it has seldom been effective in practice. Their question is: why not? and they offer three general answers. One group faults "the system" for using participation for its own ends, and allowing only symbolic rather than meaningful participation; in short, for manipulating citizens by offering, but not delivering on, participation. Another group focuses on problems in the decision-making process, including its closed nature, lack of public access to information, control by professionals, and the tendency to favour elite participants. A third group explains the lack of effective participation by looking at the participants themselves, who are not interested or informed enough, and do not have the appropriate skills, experience, or resources to participate effectively.

D. Theoretical: The items in this category differ from the others in that they offer a more serious attempt to analyse citizen participation from a theoretical perspective. Some of them do try to bridge the gap between political theory and pragmatic citizen participation. The authors here raise some fundamental questions: what are the goals or ends of participation? To what extent is decision-making shared? If it is shared, is power really redistributed, or does shared decision-making simply confirm the influence of economic and social elites?

METHODOLOGICAL ISSUES

In the literature under review, and in further research, the main methodological issues are the definition of concepts, operationalization, and evaluation. In the existing literature, definitions of citizen participation are often very vague (so that a wide range of experiences are given the same label) and operational definitions can be very narrow (in one example, "more participation" meant giving the public more advance notice of an impending decision).

This problem is equally difficult in the context of the broader issue of public participation, rather than citizen participation. What becomes clear, however, is that it is important to have some agreement at a normative level before these methodological issues can be addressed. In other words, we need to explore what kind of public participation we want, or what our goals are for public participation.

GAPS IN KNOWLEDGE

From the narrow perspective of citizen participation, there are several gaps in knowledge, including the conceptual gap between democratic theory and the practical efforts to make citizen participation work. From the broader perspective of our working definition, a different set of gaps in knowledge can be identified, at both the normative level (what kind of public participation do we want?) and at the empirical level (why do people participate in their community? is participation amenable to intervention? has the nature of public participation changed in the past twenty years?). Although the Framework for Health Promotion serves as a guide to understanding Achieving Health for All, it offers little direction on the normative questions that need to be settled. For example, on the subject of public participation, the discussion does not go beyond affirming the value of self-help groups as a way to help people cope with and improve their circumstances. It would be helpful to develop the concepts involved in public participation. The tentative categorization of goals of public participation that we gave at the beginning of this report (for social or recreational ends, for individual, group, or community betterment, to influence government decision-making) must be explored further. This exploration should take place within the context of a refined Framework document.

There are also some empirical questions that can be investigated. Perhaps the most important gap in our knowledge is the gap between the *actual experience* of participation in the community and the much smaller range of experience discussed in the literature. The literature is not a representative or unbiased sample of what is actually taking place. As a result, we do not have an accurate picture of how participation takes place in Canada, either in health or in other fields, nor do we have a rea-

sonable inventory of existing participatory approaches or mechanisms.

Some of these gaps are thrown into sharper relief when we focus on public participation in health and health promotion. For example, is participation in self-care a prerequisite for participation in collective health promotion? Can we really foster public participation in health promotion, and expect people to become involved in preventive activities, if decision-making about illness is left almost entirely to physicians and other health professionals? How widespread are agencies that offer community-based health and social services and how do they get input from their communities?

AGENDA FOR ACTION

Our action agenda is based on the gaps in knowledge that we have identified. We suggest five areas for research and action:

1. *Conceptual development of public participation:* It would be helpful to have a clearer picture of what public participation is and why it has been identified as desirable. We have outlined some goals for public participation, but these should be discussed and developed further. A similar exploration of self-care and self-help/mutual aid should be conducted. There are two parts to this work: an exploration of the ideas, and a Health and Welfare Canada statement outlining its position on these questions.

2. *Evaluation of current experience with participation goals:* Each of the goals we have identified for public participation should be examined in the light of experience. For example, where participation is aimed at purely social and recreational goals (the first goal), we can ask whether existing policies and commitments encourage broad public participation (e.g., by support for community sport and recreation) or emphasize excellence (e.g., by support for elite athletes).

The second goal of participation is the improvement of the group or community. To further this goal, we need a better understanding about the role of the voluntary sector in Canada and how it has changed over time.³ This aspect of participation is generally ignored in the citizen participation literature, although in many ways it is

3. There is some research in this field that could be used as the basis for further discussions. Such research includes work done with Secretary of State Canada on the contribution of the voluntary sector, the 1981 survey of volunteer activity attached to the Labour Force Survey, and a Gallup survey on volunteering commissioned by National Voluntary Organizations and Canadian Council on Social Development (CCSD).

the key to a more participatory society. It is clear that important social changes, such as increased mobility and higher rates of female participation in the labour force, have had a significant effect on the voluntary sector, but we do not fully understand the nature of these changes. Other developments, such as the increase in unemployment during the recession, have had indirect effects (e.g., increasing demand for food banks) but they are not clearly understood either.

With respect to the third goal (influencing government decision-making) our knowledge is somewhat greater. Research in this case could take one of several directions: we could systematically review the results of the U.S. experience with "maximum feasible participation", to see if the lessons learned are applicable to Canada and, if so, to what extent. We could also encourage consultations with community groups and decision-makers to get a broader empirical base about the Canadian experience with participation in government decision-making.

3. *Discussion of the relationships among self-care, self-help/mutual aid, and public participation:* This is largely empirical research, based on the definitions and concepts developed above. Such research could inquire into whether these activities represent a hierarchy of involvement (e.g., does self-care occur before self-help, which in turn occurs before public participation?), or whether they relate in other ways (e.g., does self-care increase as a result of either self-help or public participation?). In order to develop strategies to encourage these activities, it is also important to understand their similarities and differences (e.g., is it generally the case that those engaging in self-care are concerned with a range of issues, like diet, alcohol consumption, appropriate illness management, etc., while those engaging in self-help and public participation tend to focus on a single issue, like alcoholism or bereavement or environmental management?).

4. *Study of the effectiveness of existing institutional arrangements in fostering participation:* It would be useful to examine existing structures, mechanisms, and organizations in health from the point of view of participation. Four distinct categories can be identified: health planning councils, community-based health and social service agencies,⁴ self-help/mutual aid organizations, and health care facilities (including hospitals and clinics). To what extent do they permit or encourage public participation? How effective is the resulting participa-

4 A major study done for the Rochon Commission, comparing such agencies in Quebec and Ontario, was made public in February, 1988. The author, Jean-Bernard Robichaud of the CCSD, has also received funds from Health and Welfare Canada to expand the comparison to include agencies in all provinces.

tion? Are some potential participants consistently excluded from the process?

5. Participation in elaborating the Framework and recommending priorities for research: Although this recommendation does not emerge directly from our focus on public participation, we would like to support a "think-tank" recommendation and to recommend that a group of researchers and practitioners representing a broad range of disciplines explore the Framework and develop it further. As mentioned earlier, they should pay particular attention to the relationships among cells (for example, mutual aid might be considered a way to enhance coping, but can it be used to tackle health inequities?). We would also like to recommend that research priorities be established for the Framework *as a whole*, and not on a cell-by-cell basis. It may be necessary to focus attention on two or three cells in particular, either because of their intrinsic importance or because they have major gaps in research.eat

POLITICAL AND SOCIAL IMPLICATIONS

Based on the view of public participation discussed here, and on the experience of the Canadian Council on Social Development with participation, there are three main points that should be considered under the heading of political and social implications. First, because encouraging participation involves giving more power to individuals, groups, and communities, it creates antagonism on the part of those whose power is diminished.

Second, if public participation in health is to be successful, people need experience with participa-

tion in other spheres of their lives as well, particularly in the workplace and in schools and colleges. It is unreasonable to expect people to become active and involved in health if most of their experience is in institutions that do not permit their involvement.

These two points have special significance in health because, at present, responsibility for health and for sickness care is largely given to, and assumed by, professionals. Such an approach offers remarkably few opportunities for public participation. Encouraging genuine public participation requires a profound acceptance of the right of the public to participate, not simply in the formal process of resource allocation (the distribution of health spending and, increasingly, of cutbacks), but in all decisions affecting health and health care. How can we expect people to take responsibility for their health when they are excluded from decisions about their own illnesses?

Finally, social and economic decisions made outside the health care system have a crucial bearing on health. Fostering public participation in health in the broadest sense is, therefore, not simply a health issue. As public-health reformers understood in the early years of the twentieth century, improving health was not only a question of vaccinations and a safe water supply but also of better housing, adequate income, a safe workplace, and a healthy environment. The challenge for fostering public participation in health now is to recognize and accept the political and social implications of health for all.

PUBLIC INVOLVEMENT IN HEALTH PROMOTION AND DISEASE PREVENTION*

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*** Summary version**

HIGHLIGHTS

- While there is general consensus in the literature that the public must be involved in determining research priorities and methodologies, and in conducting and evaluating research into public participation (increasingly referred to as "public involvement") in the health promotion/disease prevention field, there is little agreement on the desirable extent of involvement, or how it can be achieved.
 - The fundamental dimension of the definition of public involvement in health is empowerment of the public in relation to political structures, health professionals, health managers, and health systems. It is seen as a right and as an essential means for achieving societal goals.
 - The implementation of public involvement must include:
 - the presence of a number of prerequisites (e.g., a well-informed community, willing to accept responsibility and empowerment);
 - various preparatory activities (e.g., identifying gaps in community health knowledge and awareness); and
 - development of a formal mechanism (e.g., board, council, committee) for interactions with the public. This would require much preparation by the community, the political/government system, health care professionals and institutions.
 - The numerous and varied obstacles to public involvement identified in the literature may be classified as relating to:
 - the nature of the community/public/consumer;
 - the overall political and social relationships between community interests, health professionals and establishments, and political and bureaucratic mechanisms; and
 - operational issues such as cost, selection of public participants, differences in perception of need between participants.
 - Numerous ethical issues and implications of public involvement must be considered.
 - Two broad areas for future study, analysis and research in the health promotion/disease prevention field are:
 - continued study and clarification of the appropriateness of different research methodologies and approaches to public involvement in decision-making; and
 - continued research directed at a clearer definition of the basic assumptions, concepts, issues, questions, methodologies and models related to public involvement in decision-making.
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BACKGROUND

The focus of this analysis is on concepts, mechanisms and issues related to public involvement in decision-making on policies and activities affecting health and well-being, rather than on involvement in actual health promotion and disease prevention activities themselves. Most of the literature is comparatively recent, dating from the 1970s and 1980s. However, the roots of the burgeoning interest may be found in a number of earlier and still ongoing developments, which include:

a) the community development movement of the post World War II era with its recognition of the central importance of community involvement in and commitment to the success of actions aimed at community betterment, whether in the context of socio-economic development in the Third World or in that of economically developed societies.

b) the emergence in the 1950s and 1960s in many countries, in particular the liberal democracies, of mass movements concerned with a range of issues of widespread public concern which many people felt had to be brought forcibly to the attention and conscience of their particular society. For example: the prevention of nuclear war; human rights; the civil rights movement in the United States; the anti-Vietnam War movement; the women's movement; and the protection of the environment.

c) the mushrooming of self-help and mutual-help movements reflecting the widespread feeling that health and health care should not be so dependent on formal health services, professionals and high technology. Central to this is the belief that people themselves must take on more responsibility and exercise power to come to grips with their perceived needs and expectations for well-being and health in the fullest sense.

d) the growing recognition that human health and well-being result from improvements in a range of interacting social factors, of which formal health services are only a part. The comprehensive definition of health in the 1948 Charter of the World Health Organization, then regarded by many as excessively visionary, has been expanded and enhanced by a series of national and international analyses and statements, including those in Canada (Lalonde, 1974; Epp, 1986; Spasoff et al, 1987), the series of reports from the United States Surgeon General in the late 1970s and early 1980s, the Declaration of Alma Ata (WHO, 1978), and the subsequent numerous statements and target-setting documents by the regions of the World Health Organization and by many other countries. All this is in part a direct response to the world-wide goal of health for all by the year 2000. A major thrust of these statements of purpose is public involvement in health. The Ottawa Charter for

Health Promotion (1986) takes the conceptualization a step further with the primacy given to health promotion as the ultimate approach.

DEFINITION OF TERMS

The literature review and analysis revealed that public involvement in health, including health promotion and disease prevention, is conceptually complex and encompasses a range of overlapping and often imprecisely defined ideas and issues. Thus, the term "public involvement" is not used uniquely. The literature refers to community participation and involvement, citizen participation and involvement, consumer participation and involvement, and lay participation and involvement, as well as to public participation and involvement. Each of these usages is held by its proponents to have special and valuable nuances of meaning. One distinction which does emerge in the more recent literature is a growing preference, by the World Health Organization and a number of others concerned with health internationally, for the term "involvement" which is being seen as connoting a more active role than "participation". The terms "community" and "public" suggest a more encompassing and generic concept for individuals, families, groups, neighbourhoods, and larger political areas than do the terms "consumer", "citizen", and "lay", although these too are useful in clarifying ideas in some specific contexts.

WHY PUBLIC INVOLVEMENT IN HEALTH?

Public involvement in health is increasing because of growing recognition of the right and duty of people to participate in decisions that ultimately affect their well-being. This recognition arises from higher levels of education and standards of living and the resulting greater health expectations. People have less confidence in policies and decisions made solely by experts and are more concerned about ethical and resource-use considerations. The latter concern has been increased by awareness of the aging of the population and the growing importance of chronic illness and disability. Better communication has helped to make people more aware of their responsibility to be involved in decision-making so as to ensure more informed and effective results.

Many countries have taken steps to increase public awareness and to strengthen mechanisms for greater public involvement in social policy development (including health) and decision-making. Some even recognize the right and importance of public involvement in their constitutions. It is a cornerstone, along with primary health care and in-

tersectoral collaboration, as enunciated by the Declaration of Alma Ata in 1978 and for the specific goals and targets of health for all by the year 2000 set by individual countries and collectively by the international community. Recent reports from a number of countries, including Canada, stress the importance of informed and meaningful public involvement in health policy development and decision-making, with an emphasis on a broad conceptual framework for health promotion and disease prevention.

WHAT IS PUBLIC INVOLVEMENT IN HEALTH? — GOALS AND BENEFITS

Public or community involvement in health may be defined as the process by which members of the community, either individually or collectively, develop the capability to assume greater responsibility for assessing their own health needs and problems, for planning and deciding on solutions (including the actual provision of resources), for creating and maintaining organizations in support of these goals, and for evaluating and bringing about necessary adjustments in goals, targets, and programs on an ongoing basis. Health promotion and disease prevention are central themes to the overall health goal. The fundamental dimension of the definition is empowerment of the public in relation to political structures, health professionals, health managers and health systems. Public involvement is seen as a universal right, an essential element to human self-fulfillment, as well as an essential means for achieving societal goals.

HOW IS PUBLIC INVOLVEMENT IN HEALTH ACCOMPLISHED? — TYPES AND MECHANISMS

Public involvement in health may take many different forms in relation to socio-economic, cultural and political conditions. Many analysts have focused on public involvement in terms of the degree of power over and input regarding decisions about goals, the allocation of resources and implementation of programs. Various models have been developed. They include a range of involvement: from tokenism to full power; from ratification of decisions with little awareness of issues to fully informed policy-making; and from only being informed at the low end and progressing through consultation, negotiation, participation to full control with veto at the top end.

Others have analyzed public involvement as either an informative or political function, or as a series of stages from authorizing or legitimizing

through planning, governing, service-giving and evaluation. Several writers note that there must be real devolution of power and authority as well as responsibility. Another analysis identifies as important the distinction between officially-sanctioned participation (e.g., through legislation, official election, or appointment) and unofficial participation (voluntarily-developed ways of involvement in seeking to influence health policy with or without the encouragement of health authorities and providers).

Political and government mechanisms for public involvement in policy development and implementation in Canada have varying degrees of official sanction, and include: hospital boards; boards of health; voluntary organization boards; local health and service centre boards; district planning and/or advisory health councils; regional health management councils; membership on professional governing bodies; advisory committees; and, on a specific *ad hoc* basis, Royal Commissions and task forces. Voluntarily-established involvement mechanisms include a full range of self-help and mutual-help organizations.

In other countries there is a wide range of mandated and voluntary mechanisms for involvement in public policy, decision-making, implementation, evaluation/monitoring, and advocacy, such as: political parties; local, regional and higher government bodies; regional and community planning, administrative, advisory and "watchdog" councils; mass movements with or without mandated access to government; mandated local/regional self-management committees of workers and recipients of services; joint sickness funds; and a varying range of voluntary and self-help/mutual-aid activities.

WHO IS INVOLVED AND WHO IS REPRESENTED?

The issue of who is involved is relatively straightforward when the involvement takes the form of direct personal or collective health-promoting and disease-preventing actions or lifestyle changes. Non-dominant segments of society, though, often require special approaches since they may not share the same values and priorities as dominant segments or may find it difficult to become involved for cultural, language, educational and socio-economic reasons. In all cases the commitment and active involvement of recognized leaders and role models is important to widespread public involvement.

The question of who is involved in advisory, planning, decision-making, implementation, and evaluation activities is more problematic. The public may be divided into a range of categories, includ-

ing: members of the public at large; members of specific target populations or groups; people with particular expertise; elected political representatives; health professionals; health service managers; other health service workers; members of major community interest groups; and recipients/clients/consumers and their families and friends. The particular mix for a board, committee or task force appears to be closely related to the purpose, expectations for involvement, and functions of the organization or program. Some argue for representativeness as a key criterion; others for needed expertise. The mix and numbers of board members are a reflection of the actual power bases within the organization.

It is also clear that consumer/client and general community members, even when in a numerical majority situation, normally have less influence, especially in relation to technical issues, than do professional and managerial members.

PREDISPOSING CONDITIONS FOR PUBLIC INVOLVEMENT

Numerous conditions have been found to be favourable to public involvement in health. These include:

- a) a supportive political climate at policy, program development, implementation and evaluation levels;
- b) a political context in which national and provincial policies, legislation, guidelines and resource allocation take account of regional/local circumstances, aspirations and needs;
- c) a political and administrative system which promotes decentralization and regional/local responsibility and authority for decision-making;
- d) an acceptable universal level of availability and accessibility of health services for meeting basic health care needs on a systematic basis;
- e) a health system in which institutions and professionals are flexible and have experience with attempting to respond to regional and local needs;
- f) a health care system in which institutions and professionals are committed to and have experience with public involvement;
- g) experience with intrasectoral collaboration by health services and professionals and between them and cognate services;
- h) a population with sufficient knowledge and skills in organization and health-related issues and with the motivation to get involved;
- i) a community with widespread individual and collective values which gives health promotion and disease prevention high priority;

j) previous successful experience with public involvement and leadership through a variety of mechanisms;

k) a socio-cultural and political context supportive to individual and collective public awareness, knowledge, and discussion of issues and problems; and

l) responsible, responsive, and efficient information and communication at and between all levels.

IMPLEMENTING PUBLIC INVOLVEMENT

There are many factors to be taken into account in implementing strategies for public involvement in health, including health promotion and disease prevention. A carefully thought-out, stepwise process is required, which must take into account the following factors:

Prerequisites

Among the prerequisites are:

- a) a devolution of significant authority, power and control as well as responsibility;
- b) a well-informed community willing to accept responsibility and empowerment;
- c) committed and supportive health professionals, institutions, and managers; and
- d) caution not to raise unreal expectations.

Preparing the Ground

Various preparatory activities are necessary, including:

- a) determining the definition of community to be followed;
- b) assessing cultural values, perceived needs and concerns, existing motivations, goals and priorities so as to identify areas of congruence between community and health system concerns and interests;
- c) identifying gaps in community health knowledge and awareness;
- d) promoting community awareness, learning, knowledge and a sense of responsibilities, rights and powers;
- e) involving already existing community networks at all stages; and
- f) identifying potential community or target population leadership.

Developing a Structure

Finally, a structure must be developed. Some type of formal mechanism for interaction by the public is necessary (e.g., a board, council, committee, task force, etc.). Such a process demands that:

- a) goals and expectations be mutually identified, clarified, understood and accepted by the commu-

nity, the political/government system, health care professionals and institutions;

b) roles, responsibilities and powers for the public, health professionals and institutions, health system managers and the political/government system be respectively identified, clarified, understood and accepted;

c) the composition and method of selection of boards, councils, committees, task groups, etc. be clarified according to their purposes and roles. A range of selection/appointment mechanisms are identified in the literature. Special attention is needed for non-dominant societal groups;

d) the precise level of accountability be clarified both for individual members and the body as a whole;

e) appropriate orientation and training of community members on how to organize, work in groups, plan, manage and evaluate activities be undertaken. This requires earmarked resources of staff personnel, access to data in understandable and usable forms, and time;

f) community members be given ongoing support in terms of access to information and understanding; otherwise they are at a disadvantage in relation to health professionals and managers. There must be provision for the real costs in time and possible income loss related to involvement;

g) health professionals and managers on boards and as program members be also given orientation and ongoing support to help change negative attitudes and to facilitate collaborative work with public representatives and communities. Changes in education and training programs for professionals and managers are also required; and

h) organizational structures, staff, and functioning must be sensitive, open and knowledgeable about collaboration and coordination with other sectors, programs, and systems.

OBSTACLES AND PROBLEMS ASSOCIATED WITH FOSTERING PUBLIC INVOLVEMENT IN HEALTH

The literature is full of problems and obstacles associated with public involvement in health. Although varied and often affected by individual circumstances, they may be classified generally as relating to: the nature of the community/public/consumer; the overall political and social organization; and the nature of operations and processes.

Nature of the Community/Public/Consumer

Communities are often quite heterogeneous in composition, interests and concerns. Although there may be general agreement on the desirability

of public involvement, there are often problems of selection, representation, and accountability of the public members. Single-group issues may be too focused to permit consensus on broader issues. Unreal expectations and a desire for quick results can be obstacles in health promotion and disease prevention, where results may take time. Many people and groups may be relatively isolated from mainstream political, social and health system structures and find it difficult to become involved. Even when they are involved, lack of access to necessary information in a usable form can prevent their meaningful involvement. Ambiguity about precise power, responsibilities and functions can be frustrating and inhibitory, and clients or patients may fear criticizing health professionals and managers. Attention must be paid to the readiness for involvement of the community/public/consumers and to their concerns and expectations.

Political and Social Structures Affecting Health and Health Services

Meaningful involvement affects basic social and political relationships among community interests, health professionals and establishments, and the political and bureaucratic mechanisms. These groups often perceive the values and purposes of public involvement differently. The formal health system may be reluctant to or even fearful of encouraging and accommodating extensive public involvement in policy development, operational decisions and evaluation, as these relate to what are considered professional or managerial areas and issues. Rather, they may want mainly cooperation with and supplementation of their professional efforts and control. Government and bureaucracy may want legitimization of policy and enhanced implementation of programs, or they want to diffuse criticism and delay action on thorny problems. Community members may want greater direct power, apart or even in opposition to the formal political system. Governments may see certain forms of involvement as compromising their responsibility and accountability for governing.

The paradox is that meaningful public involvement can only develop out of significant community responsibility and control at all stages. Even with extensive public involvement, the nature of the decisions and system operation means that real power is complex and often spread over several political levels. Large-scale corporate health organizations and systems, especially for-profit ones, may inhibit public involvement. Non-profit ones may encourage involvement.

Operational Issues

There are important ongoing costs associated with participation to individuals and to the organi-

zations themselves. These include: personal time; member education; staff back-up; and information compilation and provision. Failure to take the costs into account may limit the ability of the wider population to participate for economic and time reasons, and may inhibit the effective participation of all community members because they have limited technical expertise in health matters.

The choice of public participants is also problematic. The poor and disadvantaged and minority groups may have little experience or patience with board functioning and become "token" or "co-opted" members. Over time they may cease to be recognized by the community as legitimate representatives. Single-interest members can hamper consensus on broader issues. Community elections, separate from local government elections, often elicit low public turnout. In general, the public's involvement in health programs, whether as volunteers, workers or in monitoring and evaluation, or just in expressing views, tends to be low and limited to relatively few people.

Consumers and providers often differ on the degree of change they wish to see. The former also tend to focus on perceived needs and organizational and power changes, whereas the latter emphasize professional concerns, expertise and practical operational issues. Both tend to emphasize short-range rather than longer-range programs. Other criticisms of public involvement on boards and councils include members' spending too much time on trivial issues or on tangible items (such as building maintenance); becoming too closely identified with the service management; and becoming used or co-opted by professional, management or other special interests, including personal agendas.

The operation of committees shows that even when participation is high and public members are a majority, professionals and managers have a disproportionate influence because of their expertise. There is also a potential for personal conflict among board members between accountability to the group or to the interest they represent on one hand, and their responsibility to the health organization and its interests on the other. Individual prejudices, stereotypes and political ideologies may also pose problems. Some members develop a vested interest in their membership and resist turnover and new ideas, with public involvement becoming almost pro forma.

Other operational problems include: the use of a bureaucratic style of communication in meetings; the nature of data and the way they are presented; complicated authority and accountability structures; and increased time commitments for health professionals and managerial staff. In general, the processes of centralization, bureaucratization, scale enlargement, professional and administrative control, and technological developments in health

and health care inhibit active community involvement and promote a more passive type of response.

Finally, there is a lack of scientific studies as opposed to general observation and opinion on the effectiveness of public involvement, perhaps due to its complex and often individualistic nature, and to its effects being felt at various political, institutional and service levels.

ETHICAL ISSUES FOR PUBLIC INVOLVEMENT IN HEALTH

Public involvement in health may cause a number of ethical problems, including the following:

- a) It is often very difficult for members of the public to judge their own best interests in the face of professional expertise and advice.
- b) Health workers may be caught between the sometimes conflicting goals and interests of the community on one hand, and the service agency/establishment or government on the other.
- c) A focus on the involvement of disadvantaged or other target populations sometimes places more pressure on them for organizing change than on the rest of society, which can lead to "blaming the victim" approaches.
- d) Although consensus strategies are those commonly used, there are occasions when more coercive strategies may be justified for the good of the wider community.
- e) Public involvement may have undesired consequences and outcomes, and knowledge of these may discourage involvement.
- f) Public involvement can sometimes be used as a means for diffusing responsibility or delaying structural change by its promoters. It may result in focusing on short-term and minor change instead of longer term and more fundamental change.

AREAS FOR FURTHER STUDY, ANALYSIS AND RESEARCH

The literature on public involvement in health policy development, planning, implementation, monitoring and evaluation reviewed for this literature synthesis consists largely of individual descriptions and analyses of personal views or experiences. Almost every writer starts from the belief that public involvement in health, and in health-system and services decision-making, is a fundamental right and good for society as well as a fundamental means for the optimal achievement of human and societal health and well-being. Relatively few take an even partly negative stance on these postulates. Some writers and reports have sought to identify and define common principles,

issues, steps, processes, and problems for public involvement in health decision-making. However, examples of attempts at rigorous and systematic testing of hypotheses, methodologies and claimed results are rare. In fact, there is considerable discussion on how such research should be carried out and the appropriateness of various research methodologies and approaches (e.g., biomedical, epidemiological, social science (including economic), and action or participatory research). Furthermore, there is little literature of an analytic research nature specifically on public involvement in decision-making in relation to health promotion and disease prevention, as distinct from health and health systems and services generally.

Thus, the areas for further study, analysis and research are numerous and widespread, but include two basic areas:

- a) continuing study and elucidation of the insights and appropriateness of different research methodologies and approaches to public involvement in decision-making on health promotion and disease prevention; and
- b) continuing research directed at a clearer definition of the basic assumptions, concepts, issues, questions, methodologies and models related to public involvement in decision-making generally and, more specifically, as applied to health particularly health promotion and disease prevention in Canadian society.

Among the more specific areas for further study, analysis and research identified in this review are the following:

- a) What is the acceptable balance between the formal political/government system (with its representative nature, constitutionally-assigned responsibilities, and powers and accountability related to the political process) and other mechanisms for enhancing public involvement in decision-making, such as community based and spontaneous "grassroots" mechanisms?
- b) In the area of public involvement in decision-making, what are the optimally-acceptable and functional roles of government, the bureaucracy, health professionals, managers and establishments with regard to the community, voluntary organizations, the neighbourhood, the family and the individual?
- c) What responsibilities and powers may be acceptably delegated to community and citizen-based organizations without compromising the mandate and accountability of governments for governing? What are the implications for decision-making in health promotion and disease prevention?
- d) What are the ways in which the public and its interests may be represented in a heterogeneous society? Which are most applicable to public involve-

ment in decision-making in health, and in particular in health promotion and disease prevention?

- e) How is accountability to the population in general, to the political structures of society, and to the various specific interests to be achieved with specific reference to decision-making on health promotion and disease prevention?

- f) What kinds of public policy encourage and enhance public involvement in decision-making and what kinds limit or deter it with specific reference to decision-making on health promotion and disease prevention?

- g) Under what societal conditions do people, individually and collectively, become motivated and mobilized towards involvement in decision-making, with specific reference to health promotion and disease prevention? How may this be sustained over time?

- h) How may differences in priorities and expectations for public involvement in decision-making among the major participants (community, government and bureaucracy, and the health system) be accommodated and reconciled, with specific reference to health promotion and disease prevention?

- i) What are the implications of and acceptable limitations to public involvement in decision-making in health, with particular reference to health promotion and disease prevention, as these apply socially, culturally, politically, economically and ethically to the society as a whole and to the health and health care sector in particular?

- j) To what extent are a planned methodology and structured process for public involvement in decision-making in health, with particular relevance to health promotion and disease prevention, compatible with the goals of authentic public involvement. To what extent are flexibility, "learning-on-the-way", and spontaneity, fundamental requirements?

- k) How can suitable methodologies and models for public involvement in decision-making in health, with particular reference to health promotion and disease prevention, be tested, compared and evaluated? To what extent are the experiences of other countries and other sectors of societal action in public involvement in decision-making pertinent and applicable? To what extent are the essential features and specific characteristics of methodologies and models judged to be more effective and successful? What should be the broadly-accepted criteria for such an assessment?

Finally, almost all writers and reports emphasize the necessity for the public/community/population to be itself involved in the definition of research priorities and topics, the development of the methodology, the carrying out of the research, and the evaluation process. But there is little agreement on the extent of the involvement or on how it is to be achieved.

STRENGTHENING COMMUNITY HEALTH SERVICES: FRAMEWORK, ISSUES AND STRATEGIES*

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* Summary version

HIGHLIGHTS

- Community health services are those provided in a community (rather than an institutional) setting, to help people maintain their independence. They address physical, mental and social needs, and are provided through organizations which have continuity and whose aims include the enhancement and maintenance of health.
 - In all the domains of knowledge reviewed, community health services have been shown to be effective. The question therefore is how to move from an institution-centred to a community-centred health service. (ie., how to establish and deliver a desirable configuration of supports and services, accompanied by appropriate allocation of funds).
 - It is necessary:
 - to establish criteria for deciding whether institutional or community-based care is appropriate in different sets of circumstances
 - to find ways of ensuring that community-based care is increasingly health-enhancing
 - to establish what constitutes comprehensiveness in health services for a given population base, and to find ways of closing the gaps in community health services, and of achieving better service coordination
 - to carry out properly controlled evaluative studies investigating the long-term effect of health promotion on community health and well-being
 - in the area of primary health care, to conduct a longitudinal study on alternative modalities (e.g., capitation, the substitution of other professionals, such as midwives for physicians, etc.), and the effectiveness of using different mixes of service-providing groups
 - to summarize the knowledge base supporting health services identified with alternative philosophies (e.g. herbal medicine, chiropractic medicine, reflexology, etc.)
 - to document the benefits of personal and family support services and to study their relative efficacy
 - to study the effectiveness of individualized approaches (e.g., case-management), their fit with other service access mechanisms, and their relevance to particular groups, such as people with AIDS or the frail elderly.
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INTRODUCTION

"Community health services" is a concept that is timely, one which provides an essential vehicle for fostering health in its positive sense as a state of physical, mental and social well-being. The process of strengthening these services forms one of three "implementation strategies" for achieving such health for all in the seminal document *Achieving Health for All* released by the Honourable Jake Epp, Minister of National Health and Welfare. The present document summarizes the major concepts, current state of knowledge and priority issues relevant to strengthening community health services. It is one of a series of documents prepared by a number of different authors related to various components of the Health Promotion Framework. Readers interested in obtaining greater detail on any aspect of the following summary are referred to the full report, which includes a list of references.

This document, like the full report, is divided into three parts:

Part I focuses on framing the concept of community health services;

Part II identifies key issues and research questions related to various elements of the services themselves; and,

Part III gives attention specifically to key issues pertaining to "strengthening" such services.

The main purpose of these documents was not to review in detail each area covered by the concept "strengthening community health services", but rather to provide an overview of the significant issues and gaps in knowledge. Data sources included: searches of various bibliographic data bases, review articles, interviews with key informants, and specific published and unpublished works to which these various sources led us.

FRAMING THE CONCEPT OF COMMUNITY HEALTH SERVICES

"Community health services" as a concept is not yet well defined. In the words of one key informant, it is a "conceptual silly putty". Yet it is important to clearly frame the concept, partly to clarify what community health services are and how they relate to other services, but, most importantly, to obtain a clear vision of the nature of what we are striving to put into place. Clarity is an essential part of any implementation strategy.

There are a variety of ambiguities in the definition as currently used. Some have to do with whether community health should be limited to services such as health promotion, prevention and

protection; others relate to whether only services organized by and located in the community (as opposed to institutions) are included, and whether community services include informal helping. In a conceptual framework aimed at clarifying these and other ambiguities, we propose that community health services can be distinguished from institutional services on the one hand, and natural helping services on the other, by the following criteria:

- they are provided to people who continue to reside in a community (as opposed to an institutional) context;
- they are actively engaged in helping people maintain their independence and autonomy;
- they address the person's physical, mental and social wellbeing; and
- they are provided by individuals who are part of an organization which has continuity and has as part of its formal intent the enhancement and/or maintenance of health.

From the foregoing, it is evident that "community health services" form one part of a continuum of services. In the process of "strengthening" it also is one of three implementation (change) strategies. Figure 1 (in the full report) illustrates their location in the centre of these two continua. Table 1 (in the full report) sets out in more detail the various Elements of the Community Health Service Concept, as well as the points of overlap with the parallel strategies of "public participation" and "coordinating healthy public policy".

ISSUES AND KNOWLEDGE GAPS IN COMMUNITY HEALTH SERVICES

A. Community-based Primary Prevention/Early Intervention

In a review of recent literature relevant to primary prevention, as well as in interviews with key informants, the predominant topic was what might be called "lifestyle-related" research. An extensive amount of work has been completed. It has taken two broad forms condition-oriented research (i.e., cardiovascular disease, cancer, etc.), and demonstration study types of projects.

In the area of condition-oriented research, it is clear that the largest single gain of a health promotion/prevention nature in the past few decades has been in addressing the adverse affects of smoking. The role of smoking as a primary contributor to coronary heart disease, lung cancer and various other cancers seems incontrovertible. There is also suggestive evidence on the effects of various diets on coronary heart disease and cancers, but firm

conclusions seem more elusive. A variety of other lifestyle studies have also been undertaken, on topics including fitness, stress management, sexual practices and so on, but it appears that the data on these latter types of topics is not yet conclusive.

Demonstration project types of study begin with an assumption of what constitutes a healthy lifestyle, and then promote these. There is evidence that lifestyle behaviours will improve (as measured by reduction in smoking, controlling hypertension, etc.) as a result of such efforts. However, a significant shortcoming of all studies is that they are rarely conducted over a long enough period of time to evaluate the ultimate effectiveness of the lifestyle changes promoted. Moreover, such studies typically suffer from other problems, such as "self-selection" of the participants, and failure to evaluate actual health outcomes (as opposed to "healthy behaviours").

Several other areas of knowledge are also worthy of note. There has been some interest in the impact of lifestyle and other measures on "mental well-being". These interests, in turn, seem to have a relationship to physical well-being. A frontier area of research involves this nexus of mental and physical dynamics through psycho-neuro-immunological research. There is suggestive evidence that positive mental processes may enhance the body's ability to withstand disease, and that negative mental processes may lead to greater vulnerability. From another domain, research on "empowerment" suggests that having a sense of control over one's environment and life may also enhance well-being (perhaps in the same way as positive mental processes).

In all these areas of research there are numerous gaps in knowledge. Research into the lifestyle areas does hold promise. The highest priority would be to:

- foster long-term evaluative studies on the effects of health promotion on ultimate health and well-being, undertaking these on entire catchment areas and compared against control areas (using an experimental or quasi-experimental design);
- encourage additional research into the interrelationship of mental and physical well-being (as in the psycho-neuro-immunological, empowerment and lifestyle research).

B. Primary Health Care

Here again, one topic appears to dominate, namely, the question whether alternative means of delivering primary health care can be more cost effective than the current arrangements. The rapidly rising cost of primary (and institutional) health care as compared to the rate of inflation has been one of the sig-

nificant prompters in this interest. Two main types of studies have been undertaken in this regard: the investigation of such alternative modalities as Community Health Centres or "capitation" systems of organizing medical care, and comparing the effectiveness of professionals such as nurse-practitioners or midwives with that of physicians.

In terms of the alternative modality data, it seems clear that greater efficiency of physician use is possible. One estimate suggests that with better resource organization we might require 15% 20% fewer physicians in Canada. At the same time, it is not clear that simply reorganizing physicians' services (assuming that this could be easily accomplished) would lead to the cost efficiencies sought. There is some argument for establishing a system of competitive models. In general, the data on effectiveness of Community Health Centres in contrast to other modalities is inadequate and requires better longitudinal and comparative data.

In contrast, the data on the effectiveness of both nurse-practitioners and mid-wives as compared to physicians seems sound and well documented. Careful comparisons showed that the quality of services they provided in their areas of expertise was as good or better than that provided by physicians. Despite these superior results, both nurse-practitioners and mid-wives have had difficulty in gaining acceptance, even though using them would be much less costly than are the current health care arrangements.

A significant omission in most studies on primary health care is that, while dealing with important issues, they do not address the central question, "Towards what end should primary health services be provided?" A significant advance would be made if present research into primary health care were redirected to focus on how primary health services might be organized to provide health-enhancing (as opposed to illness treatment) services?

Notably absent also is the question of "wellness" (a topic of some interest in the U.S.). In Canada, little work seems to have been undertaken so far that deliberately seeks to address physical, mental and social well-being (except through some of the Community Health Centres). Furthermore, there is little summarized knowledge available on health services based on alternative philosophies such as chiropractic medicine, reflexology, etc.

In summary, the following would seem to be the main research priorities with respect to primary health care:

- to undertake a longitudinal study of "alternative modalities" of primary health care for definable populations in comparison to traditional fee-for-service forms of delivery;

- to encourage the use of various mixes of service-providing groups (including variance in degree of commitment to the "wellness" concept) in such longitudinal studies; and
- to summarize the available data on health services based on alternative philosophies such as chiropractic medicine, reflexology, herbal medicine, etc., with a view to determining ways, means and appropriateness of integrating such services into primary health care.

C. Home and Community-Based Care Services

In contrast to Primary Health Care, where shifts in service have been relatively slow, there has been a significant movement towards providing more and different kinds of health care services (broadly defined) in community, as opposed to institutional, contexts. These changes have been more in the nature of a "paradigm shift", where the changes occur equally as a result of shifts in philosophy and values as on the basis of actual data. Nevertheless, there is data that supports this shift. Many of the relevant studies have been undertaken in the mental retardation and mental health fields, where the greatest shifts from institution to community have taken place. Almost without exception, the data available demonstrate that community (as compared to institutional) services lead to at least no worse and frequently much improved service, quality of living, and client outcome on other criteria. Further, it appears possible to avoid reinstitutionalization almost completely if sound community services are in place. Finally, "client satisfaction" is invariably better in community than in institutional settings. Cost comparisons lead to the conclusion that community services as a whole may not be less costly than institutional services. However, when recoverable costs are considered, community services appear to be more cost-effective.

While the physical disability and aging fields do not have a definable deinstitutionalization literature, there are comparable findings comparing well organized community services to the typical non-organized services most individuals now receive in the community.

With respect to other community-based care services such as birthing centres, there again is strong evidence in favour of the quality and cost-effectiveness of well organized community-based care as compared to institutional care.

In summary, the main research priorities would seem to be:

- to evaluate various means of moving from an "institution-dependent" to a balanced health

care service system with a continuum of community-based care services;

- to determine a set of rules on the basis of which decisions can be made as to the conditions under which institutional care is warranted. (These would need to be established separately for each of the many conditions of concern to health care providers);
- research into how community-based care for persons requiring such services can be made more health-enhancing than at present; and
- (Ruberman et al., 1984) research into what constitutes comprehensiveness of health care services on a catchment area basis.

D. Personal and Family Support Services

The evaluation literature usually incorporates personal and family support services into a broader concept of community services in comparison to either no services or to institutional services. Consequently, little research on these kinds of service per se were found.

Apart from the "face validity" of the need for these services, though, there is some evidence of the value of "social support" in enhancing health, quite apart from any instrumental assistance that personal and family support services might provide.

Two research priorities appear evident with respect to personal and family support services:

- First, there is a need to document both the material as well as the "supportive" benefits of personal and family support services, examining their efficacy in contrast both to the absence of services and that of more institutionalized forms of care. In this context, the significant continuing question revolves around the role of these services in fostering continuing independence of the persons who receive them.
- Second, the future personnel base (paid versus voluntary) of personal and family support services needs to be examined, along with the implications of expanding the number and variety of resources made available.

E. Access Services

One of the most severe problems faced by members of the community with complex problems is to find their way through the labyrinth of services. A significant amount of research demonstrates that assessment, information and referral are, on their own, inadequate. More intentional and empowered

forms of service coordination are required. One notable example is the "case management" approach. Case management systems, when provided with the means to access services (or create new ones) on behalf of clients, have been found to be highly effective and efficient. At the same time, a variety of questions remain:

- Under what conditions are such individualized processes as individual program planning, case management, etc., effective, and how do they fit with other service access mechanisms in community health services?
- Under what conditions is there merit in adapting the use of case management and individualized program planning approaches to other groups with special and complex needs of interest to community health services (e.g., the frail elderly, AIDS victims, "at risk" populations, etc.)?
- How does one best assess the quality of the individualized service planning and other access services?

"STRENGTHENING" COMMUNITY HEALTH SERVICES

A. The Critical Role of Public Participation and Public Policy In Achieving Strengthened Community Health Services

The public has a variety of roles in which its participation can contribute significantly to the strengthening of community health services. Two are dealt with in the full report—one illustrating the effectiveness of actively participating in service-planning processes that affect oneself; the other illustrating the role voluntary organizations can take in introducing new service innovations. The move towards community, historically, has been more driven by "consumer-based" publics than by professionals. As an example of this, the full report cites the major change initiated by the Canadian Association for the Mentally Retarded in the early 1970s, which has resulted in a continuing impetus towards integrated community living.

The primary public policy issue involves the question of how to create a more balanced continuum of services, ranging from natural helping to community to institutional services. Currently, the preponderance of resources are allocated to the institutional base. This issue, in turn, is related to the fundamental question of vision—what kind of health services do we wish to have in place? The fundamental research questions to be addressed include:

- What would be a desirable ratio of fund allocations to achieve a more balanced continuum of health services?
- If one were to adopt the position that community health services should not be used when natural helping services will do, and institutional services should not be used when community health services will do, what would be the desirable configuration of services and supports available in the community?

B. Achieving Strengthened Community Health Services

The databases for four major issues were considered: dynamics that result from and lead to system change; vision and principles; achieving service coordination; and, how much is enough—estimating the extent of need for community health services.

A large literature has been developed on the nature of change. Since strengthening community health services represents a significant change in the current configuration of the health service domain as well as in orientation (i.e., from "illness" to "health enhancement"), the following findings are relevant:

- innovation and change is resisted by the established order;
- change takes place on the periphery (since much of community health is essentially on the periphery, this is an advantage);
- change creates uncertainty (a major concern of politicians and professionals);
- change requires the application of sufficient resources; and
- a clear vision and value-based principles are essential to providing the certainty people require in a context of uncertainty.

A vision of community health services might be expressed as "a comprehensive, coordinated array of resources which foster positive health practices, support natural caregivers, and provide treatment and supportive services only to the extent required when less intensive measures fail". The threefold aim would be to create environments that are conducive to health, to teach people how to be well, and to provide essential "illness treatment" services to all, using the least intrusive procedures possible. The full report provides a list of ten suggested first principles from which operational goals might be set.

Operationally, one of the most significant challenges will be to create services which are coordi-

nated. Such coordination is important, both to provide services in a timely manner for persons with significant health care needs, and to gain cost efficiencies. There is an extensive literature documenting factors which are important to achieving service and resource coordination. However, there are few locales in Canada that can boast of having well coordinated community health services.

The question "how much is enough?" is an unspoken concern for most policy makers. There appears to be some fear that the need for health services will continue to escalate. This has to some extent been exacerbated by epidemiological studies of the prevalence of various conditions. However, there is reasonable data indicating that the "functional" need for services is substantially less than epidemiological estimates would suggest. For example, experience in the mental retardation field indicates that the actual rate of use of services is less than one-third of what one might have anticipated. An effective alternative to projecting need is developing a "service ideal standard" approach. This approach has resulted in the following conclusions:

- service needs are not infinite, but finite and determinable;
- the most costly services (e.g., costly residential care, highly intensive professional interventions, etc.) are needed by far fewer people than initially forecast;
- support to individual service users and their families or significant others is increasingly viewed as being both a qualitatively desirable and an economically efficient means of providing services.

Fundamental research questions that should be addressed, however, include the following:

- To what extent do the various limits to the epidemiology-like approaches to need definition in fact describe the difference between prevalence estimates and actual service utilization rates?
- With what frequency do people with various types of need actually require specialized services? (As suggested above, a summary of the mental retardation and mental health experiences documenting need estimates against actual experiences would be a welcome addition to existing literature.)
- What would an "ideal" community health service be comprised of and, what configuration of service resources for, say a population base of 100,000, would

be required to properly serve the needs of:

- the elderly in the community;
- AIDS victims;
- other groups with special needs.

To date, no well developed projections which are in the process of being tested seem to exist.

CONCLUSIONS ABOUT PRIORITY AREAS FOR RESEARCH

In all the domains of knowledge reviewed, it is clear that community-based care services have proven to be effective. The major issue, then, is not whether community based care services are desirable, but rather how to move from an "institution-centred" to a "community-centred" health service.

A second issue is the question: "how does one know when community-based care will suffice and when institutional services are required?" The answer to this may well differ from one group of service users to another. Within the mental retardation field, for example, experiences of the past 20 years have demonstrated that, just as is the case for the general population, institutional services are only required in instances of acute health care. In the area of mental health a similar pattern is occurring, although the prevailing wisdom is that acute psychiatric wards are needed for people who exhibit acute psychiatric problems. But, even in such cases there is some evidence that similar services could be provided out of community based group-type homes and day treatment programs. Significant reductions might also be made in nursing home use and in hospital bed use. So, the question remains—exactly who does require institutional (including hospital) care and what criteria should be used to decide whether institutional or community-based care is appropriate in a particular set of circumstances?

A third issue revolves around the question, "knowing that community-based care is at least as effective as institutional care, what is required to make this type of care increasingly health-enhancing?" Again, there are a variety of tantalizing bits of information, some of them pertaining to prevention and early intervention which are relevant. Variables which probably apply, but have not been well documented, include: review effective matching of services to the needs of the users; continuity of service; intensity of program intervention; the presence of a "caring attitude"; continuing contact with normal routines and rhythms; etc.

A fourth issue relates to comprehensiveness and coordination. The common concern of most needs assessments over the past several decades has been the presence of significant gaps in community serv-

ices, and the need for coordination. There is a literature on service coordination summarized elsewhere in this document. Again, the significant lead in service coordination has come from the mental health and mental retardation fields. The outstanding question of how to coordinate health services generally still remains. Except for Quebec's development of CLSCs, no other province has taken steps to resolve this issue. Moreover, the question of what constitutes "comprehensiveness"

in health services for a given population base still is an open one in all jurisdictions.

The final issue embraces the foregoing; namely, evaluative work needs to be undertaken in the form of introducing on a catchment area basis a complete continuum of health services. It will be in the process of introducing such model initiatives that the greatest progress is likely to be made in answering many of the research question posed throughout this document.

COORDINATING HEALTHY PUBLIC POLICY*

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HIGHLIGHTS

- Coordinating and implementing healthy public policy are social processes which involve developing and channeling human motivations, creating social institutions, modifying the relationship between the individual and societal institutions, mobilizing collectivities to action, and other processes which are fundamentally social in nature.
 - Although the field of healthy public policy is still conceptually underdeveloped, attention is already shifting from conceptualization to implementation.
 - The mixed-screening approach to public policy is the most appropriate for the development of healthy public policy. The characteristics of healthy public policy (i.e., it is multi-sectoral, participative, multidisciplinary and focuses on issues of equity in health) generate a need for new or revised processes of developing and implementing public policy.
 - A major research priority in the coordination of healthy public policy initiatives must address the conditions under which varying degrees of centralization enhance or impede implementation.
 - Research should investigate the extent to which ambiguity, rather than clarity, of research goals facilitates implementation.
 - There is a need to examine, through research, the impact of the social and political micro-environments on all phases of the healthy public policy process.
 - Attention to individual initiatives, as well as comparative research into coordinating healthy public policy, would enrich our understanding of the coordination process.
 - Overall, a flexible approach to research is recommended—one which takes into account the rapidity with which the coordination of healthy public policy has become important in Canada and internationally. The broad approach should recognize the present underdeveloped state of knowledge.
 - Funding priorities should recognize the importance of research in the coordination of healthy public policy.
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INTRODUCTION

The interest guiding our literature review was not so much the content of healthy public policy but the processes by which it may be achieved. We found the literature of healthy public policy itself to be largely exhortatory; it was proscriptive rather than empirical in nature. The literature appears to be highly redundant; the same ideas seem to be re-worked and traded back and forth in a process leading to a shared view or ideology concerning healthy public policy and how to coordinate it.

The literature is not, for the most part, theoretically grounded. Coordinating and implementing healthy public policy are social processes which involve developing and channeling human motivations, creating social institutions, modifying the relationship between the individual and societal institutions, mobilizing collectivities to action, and other fundamentally social processes. Yet this literature does not reference the literature of the social sciences.

A useful research strategy would be to bring social science theory explicitly to bear on the issues of coordinating healthy public policy. Our review therefore attempts to make linkages between the social science literature and the literature which is specific to the healthy public policy field.

The purpose of this final report is to provide an overview of the major issues which are analyzed in some detail in the full report.* That document makes extensive reference to a wide range of literature in the area of healthy public policy and in broader areas which have the potential to contribute to the knowledge base guiding research in the coordination of healthy public policy.

CONCEPTUAL ISSUES

The research base in the area of coordinating healthy public policy reveals a wide variety of definitions. Conceptual ambiguity exists concerning such issues as the difference, if any, between healthy public policy, public health policy and health promotion policy. Research in the area will be enhanced by careful attention to conceptualization and to definitional precision. The definitions advanced in World Health Organization documents and in *Achieving Health for All* (1986)* are recommended. Health promotion is conceived as "the process of enabling individuals and communities to increase control over the determinants of health and thereby improve their health" (Health Promotion: Concept and Principles, 1986:9).

* See page 8 for information on how to obtain a copy of the full report.

Healthy public policy is distinguished from traditional medical care policy by being "ecological in perspective, multi-sectoral in scope, and participatory in strategy" (Milio, 1987a, 1987b). Healthy promotion is one particularly appropriate strategy for improving health, particularly within developed nations. In the developing world, however, emphasis is likely to be given to the provision of primary health care services.

Canada has remained in the forefront of developing both health promotion and healthy public policy since the publication in 1974 of *A New Perspective on the Health of Canadians*, and the establishment in 1978 of the Health Promotion Directorate in Health and Welfare Canada. However, in Canada as elsewhere, attention has until recently primarily been paid to individualistic efforts to change health behaviours rather than efforts aimed at enhancing health through multi-sectoral approaches.

The conceptualization of health promotion has shifted in recent years toward a multi-sectoral approach which attends to the historical and socio-structural contexts of health and healthy behaviour. Recent Canadian multi-sectoral approaches involving healthy public policy initiatives in the areas of smoking, drug use and traffic safety provide research opportunities to learn more about coordination when such programs cross both sectoral and jurisdictional lines. These new approaches begin to make health promotion congruent with healthy public policy.

Although the field of healthy public policy is still conceptually underdeveloped, attention is already shifting from conceptualization to implementation. This is occurring at all jurisdictional levels from the international level to national, regional and local/community levels. In this shift toward implementation, the customary stages of operationalization of concepts and development of appropriate indicators to assess the extent of success in implementing healthy public policy have been, for the most part, overlooked. In order to organize a review of the literature in this area, and to identify research needs, it was necessary to develop a conceptual framework. This framework makes an analytic distinction between the process of *developing* coordinated healthy public policy and the process of *implementing* coordinated healthy public policy.

THE PROCESS OF DEVELOPING HEALTHY PUBLIC POLICY

While literature, particularly that informed by research, is sparse in the new area of healthy public policy, there exists a wealth of applicable literature

in the more general fields of policy analysis, political science, and sociology which can be brought to bear on the process of developing healthy public policy. Both concepts and research techniques can be taken from these fields.

The process of developing healthy public policy is marked by complex conceptual and practical demands: that it be *multi-sectoral* and *multidisciplinary*; that its problems are *multi-faceted*; that it views human activity in *environmental and ecological contexts*; and that it should be *participatory* (Health Promotion: Concepts and Principles, 1986). Drawing on reports of examples of innovations and on the much more frequent non-empirical discussions of innovations, we provide an overview of the preliminary steps in the policy process, those which deal with the formulation or development of public policy. We discuss barriers to the formulation of healthy public policy, and suggest ways to overcome them.

Three approaches to public policy making have been identified by Ziglio (1987a): The *rational-deductive* approach, *incrementalism*, and the *mixed-scanning* approach. The latter appears to be the most appropriate for the development of healthy public policy. Mixed-scanning approaches combine the pursuit of long-range goals with the intention to attain the rationality of an incremental approach.

Conceptual frameworks found in social policy, ecology and policy studies are useful, but need to incorporate the environment in which healthy public policy is to be undertaken. Different theoretical approaches assume varying degrees of consensus or conflict in that environment, and attribute varying importance to the role of interest groups and of widespread public participation in the policy process. Some theoretical approaches, which emphasize corporatist ideas about the importance of specific interest groups, appear to run counter to the prevailing ideology of healthy public policy, which stresses the importance of broadly-based individual and community participation in healthy public policy initiatives. Important research needs emerge in the area of the relationship between the state, interest groups, and the citizenry.

The design of healthy public policy, like policy design in general, is probably most needed under conditions which make it the most difficult to achieve, namely, conditions of uncertainty.

Many in the healthy public policy field emphasize the importance of "vision" and "shared values" as a basis for the development and implementation of initiatives. "Visioning processes" and "proactive planning" invoke a model in which shared or collective authorship of a vision of a healthy future is held to be either a necessary prerequisite for or a strong facilitator of healthy public policy development. The "Healthy Cities" movement (Duhl,

1986a) is an example. The notion that a shared vision facilitates the coordination of healthy public policy is not grounded theoretically (it would be consistent with some approaches such as structural-functionalism but inconsistent with approaches such as conflict or Marxian theories); nor has it been examined empirically.

Goal-setting is another component of the policy process that is widely advocated and, to some extent, realized—as in the Quebec Report, *Objectif Santé* (1984) and the Ontario report, *Health for all Ontario* (1987). The relationship between somewhat abstract goals, more concrete objectives and behavioural or organizational outcomes is again not clearly addressed theoretically, nor examined empirically.

THE PROCESS OF IMPLEMENTING HEALTHY PUBLIC POLICY

We have drawn explicitly on concepts from the area of planning to organize the literature concerning implementation of healthy public policy. The notions of policy-making and planning often appear to be used interchangeably. However, we view planning as an instrument for the realization of policy. Social change, with concomitant generation of uncertainty, increases the importance of planning. In addition, increasing complexity of the environment, such as is occasioned whenever policy crosses sectoral or jurisdictional boundaries, or whenever the number of players and participants is increased, also heightens the need for planning. As these are all conditions endemic to the coordination of healthy public policy, it is regrettable that planning for implementation has hitherto been neglected in the literature.

Both the possibility and the legitimacy of planning have been debated. In addition to such a barrier to planning as fear of change, resistance to change by powerful interest groups and the lack of technology or "know-how" to plan for change have been identified as barriers. Rational planning models have been judged inadequate to overcome these barriers because, in part, they neglect the implementation stage and because they cannot cope with incomplete knowledge and uncertainty.

Policy implementation may also fail to realize formally stated goals but serve hidden, unintended or symbolic functions. The dispute between proponents of "top-down" and "bottom-up" approaches to policy implementation has been vigorous and affects the legitimacy of planning in the minds of various audiences. Recently, attempts at reconciliation between proponents of both approaches have been made. Effective implementation is held to require not only clear and consistent objectives and the support of central authorities

but also skillful implementing officials and the support of interest groups. It also requires supportive socio-economic and political conditions which enhance public support. A major priority for research in the coordination of healthy public policy initiatives must address the conditions under which varying degrees of centralization enhance or impede implementation.

Research should also investigate the extent to which ambiguity, rather than clarity, of research goals facilitates implementation. Planning for implementation is a political process requiring resource allocation, negotiation and compromise. The extent to which consensus is a prerequisite for effective policy implementation is very much open to debate.

Finally, our research emphasizes the need to examine, through research, the impact of the social and political macro-environments on all phases of the healthy public policy process. As Milio argues (1987a), research attention to the "social climate" of policy in general, and health promotion in particular, is needed.

In summary, the characteristics of healthy public policy, namely that it is multi-sectoral, participative, multidisciplinary, and focuses on issues of equity in health, generate a need for new or revised processes of developing and implementing public policy.

MECHANISMS FOR COORDINATING HEALTHY PUBLIC POLICY

Healthy public policy appears to require new arrangements between and within organizations which facilitate communication and cooperation. While it is recognized that coordination in Canada is complicated by the constitutional separation of powers between the federal and provincial governments, our review has emphasized inter-sectoral rather than inter-jurisdictional coordination.

Our review suggests that coordination is defined in many ways or, as in *Achieving Health for All* (1986), it is not defined at all. In that document, however, its implicit connotation is strongly suggestive of collaboration. As such, coordination demands new approaches to policy development and implementation and new structures to support these efforts. Milio (1987a) suggests that three approaches to healthy public policy predominate, a *targeted* approach, a *policy planning structures* approach, and a *participatory structures* approach.

Targeted approaches aim at specific areas of policy such as food and nutrition or cardiovascular disease. Many recent Canadian initiatives in healthy public policy can be viewed as targeted approaches. Policy planning structures approaches are those in which mechanisms for inter-sectoral planning and policy

development are developed, spanning sectoral domains. Examples would be the inter-ministerial committees established as part of the Swedish health strategy for the 1990s, and the inter-ministerial committee recently formed in Ontario in response to recommendations of the report, *Toward a Shared Direction for Health in Ontario* (1987), of the Ontario Health Review Panel. The participatory structures approach addresses the need for widespread public participation in the policy process. It has been used in the development of women's health policies in Australia and New Zealand. It is possible to combine these approaches and, in fact, this has occurred.

When effective collaboration in healthy public policy is not attained, the failure is sometimes attributed to a lack of "political will". Other barriers are probably more important and in any case are easier to measure: lack of cooperation by stakeholders with competing interests or at different jurisdictional levels; difficulties in mobilizing public support; inexperience in the policy process; inadequate knowledge base; or ideological differences between advocates of centralist approaches and those of "grass-roots" approaches.

Research on inter-organizational relations identifies a number of conditions that may facilitate collaboration for healthy public policy. Collaboration is enhanced when stakeholders appreciate their interdependence, when the policy process is implemented by interests with high legitimacy, and when alternatives to collaboration, such as litigation, are perceived as more costly (Gray, 1985).

As a general comment on the field, it may be concluded that the empirical basis upon which to draw conclusions about factors affecting the success of healthy public policy coordination is shaky. While there is little in the way of formal evaluation or analysis of coordination mechanisms, there is a growing number of examples of attempts to coordinate healthy public policy initiatives at local and national levels. Milio (1987a) provides a rich resource of structural and procedural variations in healthy public policy around the world. Canadian examples are growing in number (see full report). Research attention to individual initiatives, as well as comparative research, would enrich our understanding of the coordination process.

RESEARCH ON HEALTHY PUBLIC POLICY

On the basis of our review, several content areas for research can be recommended, alternative designs can be discussed and mechanisms to facilitate research on the topic of coordinating healthy public policy can be proposed.

Seven content areas are discussed in more detail in the accompanying full report.

HIGHLIGHTS

- Combining research and action is an issue that cuts across the boundaries of the cells in the Health Promotion Framework. There is a crucial need to effectively combine action and research.
 - For all cells of the framework, the rational planning process can provide direction and ensure that appropriate action and effective research is undertaken.
 - An examination of the literature on combining action and research through a rational planning model illustrates several methodological issues which must be addressed. These include the need to:
 - ensure that key players value health-related statistics and that data are used appropriately within a rational decision-making climate; and
 - develop "how-to" tools to enable service providers and community groups to participate in action and research at each level of the planning process.
 - It is further recommended that:
 - objectives for action and research be set at the national level, with local decision-making bodies having responsibility for prioritizing and achieving them;
 - a comprehensive database be established that will incorporate missing health indicators. This could be achieved through a regularly-administered, national survey;
 - non-traditional research designs, and multi-dimensional approaches to action and research be given priority. Project funding should also be contingent upon the inclusion of a well-designed evaluation component which considers both process and outcome measures;
 - important methodological issues and gaps in knowledge about combining action and research should be addressed before the more specific research priority identified for each framework cell;
 - the importance of dissemination of information be recognized and that resources be allocated accordingly. Effective dissemination includes identifying target audiences and developing dissemination vehicles appropriate to the needs of each;
 - early participation in action and research by the key players will help to ensure that knowledge and information are spread, and that support is gained for the action/research process, findings and subsequent actions.
 - a well-designed evaluation component, which addresses the most effective and efficient means of promoting health, should be part of any research proposal submitted for funding.
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BACKGROUND AND METHODOLOGY

Background: Achieving Health for All

With the release of *Achieving Health for All: A Framework for Health Promotion* on November 18, 1986, the Minister of National Health and Welfare launched the Department's health promotion initiatives into exciting and challenging directions.

One such initiative was the establishment of a series of literature reviews related to each of the main components of the Framework. These reviews summarize the relevant literature, identify gaps in knowledge, outline methodological issues and suggest priority questions for research and implications for action.

The Topic: Experiences in Combining Action and Research

In addition to the nine major elements of the Framework, another topic—"Experiences in Combining Action and Research"—was added to the list of areas to be reviewed. This topic can be seen as an integral component of each element of the Framework. For each health promotion challenge, mechanism and strategy the need to effectively combine action and research is crucial.

The Approach: A Rational Planning Model

Experiences in combining action and research have been examined from the perspective of a rational planning model. Figure One in the full report outlines such a model which comprises five stages in the policy-making process:

1. Needs Assessment
2. Design of Alternative Courses of Action
3. Consequences of Alternatives and Selection of a Preferred Option
4. Implementation
5. Evaluation

Within each of these five stages both research and action are required. This report attempts to identify the crucial links between research and action within and between each stage of the rational planning model.

A literature review and key informant interviews were undertaken to identify the research and action associated with each stage of the planning process, and to discern the critical links needed to effectively combine research and action.

The literature review involved searching for published and unpublished literature. The literature outlines international, national and municipal experiences. Published material was identified through a computerized literature review and a scan of various abstracts, including those produced by the Health Promotion Directorate for the purpose of these literature reviews. Unpublished material was unearthed through a variety of avenues,

including discussions with key informants and contacts made through other activities of the Institute for Health Care Facilities of the Future.

A list was developed of key informants, people involved in research and/or program planning and implementation in projects at the local, provincial and national levels throughout Canada. The list of key informants and the interview instrument used during discussions with the key informants is included as Appendix C to the full report.

The exchange of information with other reviewers took place during a meeting held on September 21-22, 1987 enriching the information provided by the key informants. An experience shared by many of the reviewers at the September meeting was that the material contained in the unpublished literature and the information gleaned from key informants were invaluable in identifying and understanding the issues under review.

The Next Step

Key concepts, strengths and weaknesses associated with combining action and research were crystallized as the literature and informant interviews were analyzed. Factors such as the multi-disciplinary/intersectoral nature of the process, the need for national objectives and information dissemination, the influence of political will, funding priorities and public participation, and the role of healthy public policy reappeared throughout the rational planning process.

From this analysis emerged an understanding of the gaps in knowledge associated with combining action and research, the methodological issues that need to be addressed and a list of priority questions and implications for research and action.

These findings are detailed in Appendix A to the full report and are summarized in the present report.

MAJOR FINDINGS AND RECOMMENDATIONS

Introduction

A literature review and key informant interviews have been undertaken in the hope of shedding some light on experiences in combining action and research. The information was analyzed from the perspective of a rational planning model.

Within and between each of the five stages of the rational planning model, action and research are integrally linked. Action may lead to or require research and, conversely, research may lead to or require action. The two may also occur simultaneously.

Often, effective research and/or action is the result of the "right person being in the right place at the right time". The rational planning process,

while not preventing this from happening, provides parameters which enable a more focused and effective expenditure of resources.

Not surprisingly, the bulk of the information gathered through the literature review and key informant interviews was related to needs assessment and evaluation—probably the two stages that are best understood. This does not mean that little work is required in these areas. On the contrary, many of the fundamental gaps in knowledge and methodological issues that need to be addressed are related to needs assessment and evaluation.

Synthesis of the Literature Review and Key Informant Interviews

1. Needs Assessment

As expected, the process of needs assessment is generally well understood. However, work is required in the areas of valuing research, setting national objectives, focusing on the right questions, data collection, data analysis, providing relevant and usable information, and effectively disseminating this information. All of these areas must be adequately addressed at this stage in the rational planning process so that subsequent stages in the process can be successfully undertaken.

Before an attempt is made to assess needs, the value of research must be understood and appreciated:

"Research, particularly health services research, when properly planned and executed to address critical issues, is not a luxury but a necessity for the systematic evolution of improved methods and capabilities to solve problems in support of health for all strategies." (WHO, Target 2000).

"... there has been a lack of enthusiasm about health statistics and indeed, an apparent lack of understanding of their social purpose and importance." (Australian Bureau of Statistics).

The most important prerequisite for effectively combining action and research is the establishment of a set of measurable and attainable objectives. These objectives will provide a focus for all subsequent courses of action and research.

Following the models developed in Ontario, Quebec and the United States, available data can be used in conjunction with expert consultations to develop goals and objectives:

"The establishment of goals is a crucial step in strategic planning, a creative process intended to lead an organization in a purposeful direction. Goals are formulated on the basis of social, political, economic and technological realities. These goals serve as guidelines by which the needs of the community can be coupled with the available resources (monetary, material and human) to

general priorities for program development. At the same time, the goals encourage coordination between ministries within government, and between organizations, services and groups at the community level. . . Finally, health goals can provide an objective basis for evaluation of health programs, and for the planning of subsequent policies and programs." (Spasoff).

"To facilitate the efficient use of resources available for disease prevention and health promotion efforts, and to measure the effectiveness of these efforts, a process was undertaken to set specific, quantifiable objectives for each of the 15 priority areas. To initiate the objective setting process, 167 experts were invited to attend a conference in Atlanta, in June 1979. The experts were organized into 15 work groups and assigned the task of producing an initial draft of specific, quantifiable objectives for their assigned areas. The drafts of the objectives were published and circulated to approximately 3,000 individuals and organizations for review and comment. The drafts were revised on the basis of the suggestions received and were recirculated in 1980 to the Atlanta work group chairpersons, to officials within the Department of Health and Human Services and to staff of the selected federal agencies. Final revisions to the 222 national objectives were made and "Promoting Health/Preventing Disease: Objectives for the Nation" was issued in the fall of 1980." (Iverson).

It should be noted that the focus of the above is on the national and provincial level. Prioritizing these objectives and determining how they can be met should be decided at the regional and community level so as to reflect the diversity of local needs and resources.

In addition to providing a focus for the deployment of resources, setting objectives will enable research and action to be sustained through ongoing political support and funding commitments.

For research and action to be effectively linked, projects must address the right questions. A comprehensive view of health is needed, one that incorporates a broad spectrum of health-related factors such as socioeconomic characteristics, lifestyles, social support networks, housing and genetics. This broad view must also consider disease, health, cure, prevention and promotion. Both behavioural and biomedical aspects of questions need to be considered. Rather than focus in on either the individual or the environmental factors associated with a needs assessment, the inter-relatedness of these factors should be incorporated into action and research. A multi-strategy action plan cannot be designed without a comprehensive needs assessment which has been developed using research that encompasses a broad scope of health-related variables and which considers the inter-relatedness of variables.

Baseline and trend data, not snapshot pictures, are the basis for comprehensive needs assessments and subsequent courses of action. As noted by the Centres for Disease Control (U.S.):

"Many communities cannot target their scarce health care dollars to high-risk groups or to amenable problems because they are unaware of the need."

For effective planning, local and regional data are needed in addition to national data.

Appropriate data collection techniques are required to ensure the validity of the needs assessment. This may necessitate a collaborative effort involving government officials, academics, researchers, planners, service providers and target groups. The sooner all players are brought on board, the greater the probability of obtaining their support for the process, findings and subsequent action.

Reliable information sources may include both rigorous studies and "barefoot" epidemiology. While not replacing more sophisticated research, barefoot epidemiology can provide guidelines for action in the face of uncertainties (Freudenberg).

After the appropriate data is collected, it needs to be analyzed. The American experience demonstrates that setting objectives and collecting appropriate data do not ensure that the data will be analyzed or used. Setting objectives and collecting data are not all that is required in needs assessment: the data must be used.

When collecting and analyzing information, researchers and information specialists need to be cognizant of who will be using the data and for what purposes. "Knowledge for knowledge's sake" has its place, but when action and research are combined, information must be usable and policy-relevant.

Research is not an end in itself. Dissemination of information is a recurring theme in this analysis. At each stage, information that is collected must be effectively disseminated to a wide audience so as to effect the necessary changes and developments in research and action.

As stated by Mutter:

"The systematic diffusion of research results underlines the critical role that the promotion of research findings can play as a health promotion activity."

The information must be presented in such a way as to be useful to the target audiences. Many effective vehicles are available for information dissemination. The information needs to be timely, i.e. not provided months or years after the fact, but as soon as possible, so as to effect change. With advances in technology shorter turn-around times are now often possible.

2. Designing Alternative Courses of Action

This next step in the rational planning process can only occur after objectives have been set and needs assessed. As will be seen, there is a critical connection between the findings of the needs assessment stage and the research and action required to design alternative courses of action. Without measurable objectives, a comprehensive data base and dissemination of information, one cannot design effective alternative courses of action.

Knowing the needs is only the first step. How to meet these needs is the question addressed at this stage. Designs that have already been developed to meet similar needs should first be explored. However, many of the key informants remarked that such designs have not been widely disseminated.

The alternatives that have been developed need to be effectively packaged and promoted. Information dissemination is, once again, a key link in combining action and research.

If the question "what alternatives exist?" is met with either a resounding echo, or with alternatives which are not applicable to the specific circumstances, then alternatives have to be designed from scratch. The trials and tribulations of people in the field reflect some important truisms: special skills are required to design courses of action, a multi-dimensional approach is most effective, healthy public policy should be considered, many vehicles are needed, efforts should be consolidated among the various agencies and groups involved, and the design should be as flexible as possible while still meeting objectives and needs.

Policies and various courses of action must be analyzed from the perspective of their anticipated impact on health. More emphasis is needed on healthy public policy, i.e. the relationship to health of health policies and non-health policies alike and the impact of health policies on other sectors.

With multi-dimensional needs, it logically follows that a multi-dimensional approach should be designed to meet these needs. The coordination and cooperation of various government bodies, agencies and community groups are needed if a design is to be effective.

The structure of the design has to be flexible enough to evolve over time to reflect the input of implementers, clients and evaluators.

The question of who or what is to be affected, (individuals of a specific age, sex or socio-economic group, the political system, or the environment or society in general), needs to be resolved before the design can be focused.

A fundamental ingredient of any design is the complex matrix of the "powers that be". This was succinctly noted by Freudenberg:

"What administrators and educators need to know is how health policy is shaped, how national

policies get translated down to a particular institution and how public health professionals, acting in concert with citizens, can influence policy. They need to learn different strategies for political change and how to decide to use each one." This raises important questions in terms of public participation and healthy public policy, two of the elements of the Health Promotion Framework. Suffice it to say that understanding this "political" process and incorporating it into the design of alternative courses of action is as important as the other issues related to designing alternatives in terms of effectively combining research and action.

Both the existing and the newly-developed alternative courses of action need to be effectively promoted at all levels, from government agencies to local community groups and individuals.

3. Consequences of Alternatives and Selection of Preferred Option

Little of the information reviewed touches on the issue of considering the consequences of alternative courses of action and selecting a preferred option. This could be expected, particularly as, in reality, more than one alternative is rarely considered. What has come to light through information provided by key informants is that the consequences of various alternatives are often not quantified (e.g. from a cost/benefit perspective). Thus, more often than not, the chosen course is based on political, funding, or resource expediency rather than on an informed information base. Simply put, the consequences of most courses of action are not known.

There is, therefore, a need to evaluate the alternative courses of action and to select a preferred option or set of options based on these evaluations and then to disseminate this information.

The purpose of considering the consequences of alternative courses of action is to try to understand which course of action, of all those through which an objective could be met, is the most effective and efficient?

As discussed in the section on designing alternative courses of action, a multi-dimensional approach is often the most effective intervention. This may include different programs working together to achieve one objective. When evaluating consequences under these circumstances, the potential synergistic or antagonistic effects of combining programs must be considered.

In selecting a preferred option, information and tools need to be given to the stakeholders so that they can make the decision. People are needed who have experience in conducting meetings and building consensus. While no decision is value free, information is needed so that a rational

decision-making process can be used to the greatest extent possible.

As information about the consequences of the various alternatives becomes available, it needs to be effectively disseminated so that effective designs can be implemented.

4. Implementation

A wealth of questions and some answers appear at this stage of the rational planning process. What is it that gets research translated into action: political will, public participation, support of service providers and the research community, the involvement of the private sector, legislation and regulations, and/or funding commitments? The answer seems to be an ethereal combination of all or most of these factors.

Barriers to implementation, as noted by Kreuter, include formidable political, philosophical and economic barriers which need to be realistically acknowledged. Inter- and intra-institutional coordination and cooperation is needed together with government support for research and action. Again, research needs to be valued.

Many players are responsible for ensuring that research and action are implemented. Political will is of paramount importance:

"Given the magnitude of the task of attaining health for all, strong political will and the mobilization of public support are fundamental prerequisites for launching the necessary action and for ensuring the clear commitment of the country as a whole to the objective of health for all." (WHO, Target 2000).

Of course, support is needed at all levels of the system, from the political to the grassroots level. Again, participation of the public and the research community must be sought for the successful implementation of action and research, particularly in a pluralistic society such as Canada.

In the literature, the private sector is also acknowledged as having a strong lobbying voice. While there is some controversy as to how or if legislation and regulation should play a role in health promotion, there is little doubt that they have played an important role in implementation.

As noted in many reports and by key informants, action and research often suffer from a lack of continuity, inconsistencies, interruptions and delays because of changes in funding mechanisms.

Having reviewed many of the key variables involved in implementing research and action, when all is said and it is hoped done, the most important component of effective implementation strategies is that once these formidable variables have been identified, they must work collaboratively to effect change.

Once the inertia has been overcome, research and action can be successfully implemented. Compromises are even possible which allow research and action to work effectively together. In a case study described by Coulter, the most frequent areas of tension experienced when combining action and research were in the areas of subject recruitment, allocation of resources including time and funds, data analysis and evaluation. However, "this project with its flexible format and supportive efforts, demonstrated that rigorous research can be conducted in a service setting in cooperation with service providers, even in such a sensitive area as sexual abuse of children."

Yet again, the dissemination of information plays an important role in the efforts to combine action and research. The dissemination of information should be an integral component of all ongoing projects.

5. Evaluation

"Evaluation of Health Services is the systematic and scientific process of determining the extent to which an action or sets of actions were successful in the achievement of predetermined objectives. It involves measurements of predetermined objectives. It involves measurement of adequacy, effectiveness and efficiency of health services. It renders possible the reallocation of priorities and resources on the basis of changing health needs." (Hogarth 1978, cited in Macpherson).

Why evaluation is needed is well understood, why it does not get done is yet another component of combining research and action.

Many methodological issues and questions are raised in association with the evaluation. Many of their answers reflect earlier themes of valuing research and evaluation, needing a rational climate of decision making, ensuring adequate funding, and providing tools to facilitate research and action.

Unrealistic expectations of health promotion projects often make evaluations seem very threatening. With definable, realistic program objectives and a clear understanding of the potentially long time lag which may occur before discernible changes can be measured (an issue often associated with health promotion projects), evaluations need not be threatening. In health promotion, evaluators need to value the gains made when the seed of information and change has been planted.

Proper evaluations require specific skills. In a review of evaluations undertaken by projects funded by the Health Promotion Directorate, it was noted by Daker that the evaluation components most in need of attention were objectives, evaluation types, evaluation design, sampling methods, attrition and data collection. Tools have been developed by many groups to facilitate better evaluation designs and implementation.

Both qualitative and quantitative data should be valued in evaluations. For evaluations to be undertaken there must be some sense that the results will be used.

There are two sides to the funding issue associated with evaluations. Sufficient funds for both process and outcome evaluations should be included as part of any project funding. On the other hand, projects should not be funded unless they include an appropriate evaluation component.

There is some debate as to whether internal or external evaluators should be used in the evaluation process. The bottom line is that some type of evaluation should be undertaken with the ultimate aim of producing an unbiased account of the project's ability to effectively and efficiently meet its stated objectives.

And yes, once again, the results of the evaluations should be distributed to many audiences using many vehicles.

GAPS IN KNOWLEDGE

We need to know:

- what the health objectives are at the national, provincial and local levels. We will then be able to focus health promotion action and research initiatives;
- how to identify and measure health status indicators. Specifically, we need to fill the gaps in the types of health-related data that are gathered, including an emphasis on health rather than disease, behaviour rather than institutional utilization, and encompassing a broader spectrum of variables (e.g., housing, socioeconomic characteristics, and quality of life indicators);
- what the trends and baseline data are. Simple snapshot glimpses of health needs are inadequate. For useful trend data to be developed, the definitions and measures of the variables being collected must be consistent over time.
- how intervening variables interact. Specifically we need more information on the potential synergistic and/or antagonistic effects of combining multidimensional strategies to meet multidimensional needs;
- how equity can be assessed and monitored within the present health care system; and

- the results of process and outcome evaluations of alternative courses of action.

We need a better understanding of:

- how the political system operates: how research is translated into policy and policy into action; and how and where to influence this system at both the federal and provincial levels;
- how to design alternative courses of action;
- how to analyze policies and actions and discern their impact on health;
- how to conduct effective evaluations; and
- who the audiences are and how best to effectively disseminate information.

METHODOLOGICAL ISSUES

Methodological issues associated with experiences in combining action and research are concerned with the areas of:

- valuing research. We need to ensure that the importance and social purpose of health-related statistics are well understood and valued by both government and public agencies, and that a rational decision-making climate exists to allow information to be used.
- creating usable, policy-relevant data. Projects need to provide for information that can be used to effect change.
- focusing on multi-dimensional approaches as opposed to the single risk factor approach.
- establishing measurable and attainable objectives for each project.
- legitimizing "softer" data.
- developing "how-to" tools. Tools are needed to enable service providers and community groups to participate in action and research at each level of the planning process, particularly needs assessment (data collection and analysis), designing alternative courses of action, and evaluation.
- incorporating flexibility in the design of alternative courses of action, implementation strategies and evaluation of research and action. Projects need time to evolve to their most effective state.

- disseminating information effectively, i.e. identifying target audiences and then developing vehicles appropriate for each audience. Information dissemination should be undertaken at each stage of the planning process.
- coordinating and consolidating the efforts of individuals, agencies and governments.
- encouraging early participation by a range of players so as to disseminate information and gain support for the process, findings and subsequent actions.

PRIORITY QUESTIONS AND IMPLICATIONS FOR RESEARCH AND ACTION

The recommendations listed below emanate from the analysis of the literature review and key informant interviews. Just as each stage in the rational planning process is dependent on the completion of the earlier stages, the following recommendations are listed in order of what needs to happen first, e.g., the setting of national objectives before designing and evaluating alternative courses of action.

Many more recommendations could have been made. However, the recommendations presented here reflect the action and research which is within the jurisdiction of the Working Group on Health Promotion/Disease Prevention Research Priorities, the National Health Research and Development Program and the Health Promotion Directorate.

It is recommended that:

1. Objectives be set at the national level with the methods for achieving and prioritizing these objectives being left to the discretion of local decision-making bodies. Once the national objectives have been established, funding commitments will be needed to meet these objectives. Funds will need to be allocated for a mid-course review.
2. A comprehensive data base, which incorporates the missing health indicators, be established. The federal government, in consultation with provincial counterparts, should support an on-going population-based health survey, conducted, for example, every three years in order to provide a comprehensive data base which will provide baseline and trend data. Such a survey should encompass the missing health indicators and should consider the interaction of intervening variables. An "honest broker" may facilitate in initiating and conducting the survey. As noted in the "Report of the Panel on Health Goals for Ontario," August

1987, p. 105, the cost of such a survey will not be prohibitive:

"Once the initial developmental work has been done, the cost of each such survey would be less than \$1 million, which is roughly equivalent to the operating costs of just one bed in a teaching hospital over the three-year period."

3. Multi-dimensional approaches to research and action be given priority over single factor approaches and that the evaluation of potential synergistic and/or antagonistic effects of such efforts be funded.

4. Non-traditional research designs be considered for funding. When evaluating the research design of a project which may include behavioural, environmental, and/or qualitative factors, this project should be afforded the same consideration as controlled experimental designs which incorporate only biomedical, individual behaviour and quantitative measures. Also, in determining various alternative courses of action, qualitative research such as focus groups and Delphi methods should be encouraged.

5. Project funding be contingent on the inclusion of a well-designed evaluation component including both process and outcome measures and that funding levels reflect the need to undertake effective evaluations. Evaluations must address the question of the most effective and efficient means of preventing disease and promoting health. These measures should encompass more than just the cost elements associated with a course of action. For example, quality of life indicators should be considered.

6. The dissemination of information be recognized as an integral component of all research and action and that funds be allocated accordingly.

CONCLUSION

The priorities listed above will be considered by the Working Group on Health Promotion/Disease Prevention Research Priorities in conjunction with the priorities identified by the other literature reviews.

The other reviewers will have determined the priorities for a particular element of the Framework, e.g., self help or healthy public policy. However, before these priorities are acted upon, they should be considered from the perspective of the rational planning process.

The identified gaps in knowledge, methodological issues and priority questions related to experiences in combining action and research should be addressed before the more specific priorities identified for individual elements of the framework are acted upon. Whatever the area of interest, the rational planning process can provide direction and ensure that appropriate action and effective research is supported and undertaken. The priorities outlined in this report should be seen as integral and complementary components of each one of the elements of the Health Promotion Framework. For example, within the challenge of reducing inequities, what are the objectives, who are the key stakeholders, what level of political support exists, what evaluative measures will be undertaken, and what forms of information dissemination have been considered?

Once answers to these broad questions related to the rational planning process are provided, specific issues within the discipline can be addressed.



METHODOLOGICAL ISSUES IN THE STUDY OF PROGRAMS FOR HEALTH PROMOTION

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No highlights have been prepared for this paper, which was commissioned separately from the literature reviews to examine methodological issues related to the study of health promotion programs.

INTRODUCTION

The cost of a program for health promotion can be substantial. Therefore, it is essential to acquire evidence that the program will be effective before deciding to implement it on a large scale.

To acquire the evidence, research is almost always necessary. The methods of research into the effectiveness of health promotion programs are utterly different from those used in physiological or biochemical experiments, and substantially different from the methods used in the evaluation of therapeutic agents for the cure or alleviation of disease.

In order to discuss the research methods required for the study of health promotion, one must begin by classifying the various programs. I will classify them according to their objectives, because the methodological issues are closely related to the objectives.

CLASSIFICATION OF HEALTH PROMOTION PROGRAMS

1. Programs designed to increase the participation of citizens in decisions related to health and health care (the term "empowerment" has been applied to such programs and I will use this term henceforth).

2. Programs designed to make the environment more conducive to health.

3. Programs designed to alter the lifestyle of individuals.

The ordering of this classification is deliberate, because I believe that a widespread change in lifestyles is unlikely to occur until members of the population have a sense of participation in health decisions and have confidence in the healthfulness of their environment. It is true that improvements in lifestyles have occurred, but these have been concentrated in the upper classes of society. The reason for this goes beyond the relationship between education and responsiveness to health information. Although there is such a relationship, I doubt that it explains the whole phenomenon. The lower echelons of society will be resistant to lifestyle changes as long as they perceive that they have little input into health policies and as long as they believe that environmental factors affect their health more strongly than do lifestyle factors. We must be willing to concede that some of their perceptions and beliefs may be correct.

RESEARCH INTO THE EFFECTIVENESS OF EMPOWERMENT PROGRAMS

The method of program review is probably the most appropriate way to begin. A structured program review would allow us to examine the following:

1. The extent to which the goals of the program were defined in measurable terms.
2. The methods used to attain the goals.
3. The difficulties and costs encountered in implementing the methods.
4. The extent to which the goals were met.

Only after this information has been obtained would it be reasonable to consider the more rigorous research method of experimentation. It is likely that the review method of evaluation will show that some programs are so lacking in feasibility that further study would be unwarranted. The experimental method should be reserved for programs that survive a review, and where alternative methods for meeting the goals of the program are apparent.

The design of experiments to test the effectiveness of empowerment programs will not be discussed further, because many features of such experiments are similar to those of experiments for determining the effectiveness of environmental programs for health promotion. In both cases, the unit of observation is almost always the community rather than the individual.

RESEARCH INTO THE EFFECTIVENESS OF IMPROVING THE ENVIRONMENT

This category of health promotion is a broad one. It includes pollution abatement, occupational hazard control, improvements in highway design, the addition of prophylactic agents to the environment (e.g., water fluoridation), the manipulation of alcohol and tobacco prices, the regulation of the content of commercially-produced foods and many other health promoting efforts directed at the environment.

The non-experimental approach must be given due consideration before proceeding to the vastly more expensive method of experimentation. "Natural experiments" can be exploited, as exemplified by the study of municipalities which differed in their water fluoride content for purely geological reasons. Excellent studies of this type were carried out, with careful pairing of municipalities so that other variables likely to affect dental decay were controlled. It is interesting to note that the non-experimental studies produced results almost identical to the experimental study of fluoridation in Kingston and Newburgh in New York State.

By today's standards, the experiment in New York State would be regarded as flawed, for two reasons. First, the sample size could not be regarded as the total population of the two cities, since residents of one community resemble one another more than do residents of two separate communities. Thus, the sample size in this experiment lay somewhere between two (the number of

communities in the experiment) and the number of citizens in the two communities. Further discussion of group randomization and the statistical issues involved is given by Buck and Donner (1982)¹ and Donner (1987)². Second, the experiment was not double-blind but only single-blind. The examiners of the children's teeth were blinded to the residence of the children, but the populations of Kingston and Newburgh knew the status of their water fluoridation. Therefore, it is conceivable that the residents of the fluoridated community "assisted" the experiment by maintaining a better standard of oral hygiene.

These remarks are intended to emphasize the fact that experimental studies of environmental programs for health promotion present many challenging problems in design.

Although the non-experimental approach is usually less expensive, I must draw attention to its limitations. These are particularly evident when the program is concerned with factors other than the physical environment. Let us take as an example legislation to increase the price of alcohol, or to limit access to drinking establishments. Suppose that one community exercises more control over the availability of alcohol than another community. It is possible that members of the first community have reached the stage of regarding alcohol consumption as a health hazard and have altered their legislation accordingly. The lower incidence and mortality from alcohol-related disease in such a community would therefore be a consequence of the attitude of its citizens to alcohol consumption, rather than a consequence of legislation affecting the availability of alcohol. The same problem could affect other non-experimental studies of environmental health promotion. For example, legislation of speed limits and the use of seatbelts could reflect personal concern about motor vehicle accidents, rather than the effects of the legislation *per se*.

The non-experimental approach is useful as a preliminary method for evaluating environmental change, but caution must be exercised in the interpretation of such studies. If it is likely that an environmental change is the result of change in the attitudes or behaviour of individuals, we must avoid the unwarranted conclusion that the environmental change in itself was responsible for an improvement in health. Therefore, before undertaking a non-experimental study, we should carefully consider the possible nature of the cause-and-effect relationships in the situation under investigation.

The non-experimental approach to the evaluation of environmental programs can be enhanced by use of the before-after design, which reduces the influence of extraneous variables. For example, morbidity and mortality from respiratory disease could be compared during

two periods, one before and one after the introduction of air pollution controls into a community. The opportunity to use the before-after design may be lost because data for the baseline period have not been collected. The desire to quickly implement an environmental program is often in conflict with the need to collect data for the "before" period. Patience and foresight can prevent this from happening.

RESEARCH INTO THE EFFECTIVENESS OF LIFESTYLE CHANGES

Much of the research in this area has been observational rather than experimental in design. The benefits of weight loss, smoking cessation, increased exercise and other changes in behaviour have been deduced from studies that compare people who do and do not make such changes, or from before-after comparisons of people who undertake alterations in lifestyle. Although the results of these investigations often appear convincing, a residual doubt always remains. Was it the change in lifestyle, or was it some unmeasured characteristic of the people who successfully made the change, that led to an improved state of health?

For this reason, attempts have been made to use the experimental approach, in which the investigator rather than the subject imposes the change in lifestyle. The experimental approach unfortunately is very difficult to undertake. First, very large numbers of subjects are required, especially if the health outcome of interest is rare, or even moderately rare. Thus, for example, experimental studies of the value of exercise in the prevention of myocardial infarction are carried out on high-risk subjects rather than on samples of people from the general population, in order to secure a sufficient occurrence of the disease which exercise is intended to prevent.

Other difficulties with the experimental approach can be illustrated by the Ontario collaborative study of exercise for the prevention of recurrent myocardial infarction (Rechnitzer et al., 1983).³ This was a two-group experiment, in which patients were randomly assigned either to heavy exercise training or to a program of light exercise. The latter was used in order to control for the placebo effect associated with enrollment in a group program. At the end of the experiment, the rate of recurrent infarction was almost identical in the two groups, but lower than in previous observational studies. Three interpretations of this result were possible: first, that light and heavy exercise are equally preventive; second, that belonging to a group has a preventive effect, and third, that the exclusion of patients for whom exercise was considered inappropriate led to a better

outcome than expected in both groups, quite unrelated to exercise. The problem of interpretation could have been reduced by having a third group kept under observation but not given any group activity. This strategy could not be adopted because even in a multicentre experiment the supply of patients was not large enough to allow for a three-group design.

Another serious problem was non-compliance among the patients enrolled in the trial. This occurred in both directions. In the heavy exercise group, nearly a third failed to achieve the cardiac training that heavy exercise was intended to induce. In the light exercise group, 15% of patients achieved cardiac training on their own—in other words, contamination of the control group was substantial. In both groups, there was a high rate of drop-out during the course of the experiment. It could be argued that these difficulties would have been avoided if non-compliant subjects had been excluded from the experiment prior to randomization. But determination of compliance in a lifestyle experiment is a more difficult process than in a therapeutic experiment. In the latter, patients can be given a medication for a brief trial period and their actual intake of the medication can be measured by various techniques. In a lifestyle experiment, a trial period for measuring compliance would have to be lengthy and would tend to enhance contamination of the control group. It may be possible to overcome this difficulty in the future if compliance can be measured without the subjects actually engaging in the lifestyle change under study. Psychological tests that would give a valid prediction of compliance with a specific behavioural change do not yet exist, as far as I know. The development of such tests would make an important contribution to the experimental investigation of the value of lifestyle modification.

If the observational design leaves unanswered questions and if the experimental design is difficult to implement, where do we go in the evaluation of lifestyle change? I would like to offer one suggestion.

We would start with an observational study of individuals. If the results were sufficiently promising, the problem of self-selection inherent in such studies might be circumvented by turning to a multiple time-series analysis. Suppose, for example, that observational studies have shown that weight loss by the obese is followed by a reduced risk of heart

disease. One would then proceed to examine various populations to determine the trend in the prevalence of obesity over time, and the time trend in the incidence of heart disease after a suitable lag period. No correlation between the two time trends would be expected if weight loss were actually of no value but only appeared to be of value, because people least predisposed to heart disease succeed in reducing their weight. Therefore, if a correlation were found, it would strengthen the evidence from the observational studies of individuals.

The suggested combination of the two non-experimental approaches is not, of course, without flaws. In the time-series study, other factors might have influenced the incidence of heart disease over the period following a change in the prevalence of obesity. If these factors could not be examined, a problem would remain.

Time-series data for lifestyle variables are not at present widely available. If this approach is considered to have merit, the periodic collection of such data should begin at once. An encouraging step in this direction has been taken in the United States with the Behavioral Risk Factor Surveillance System now underway in 22 states (MMWR, 1986).⁴

CONCLUSION

Considerable ingenuity is required in the design of research to evaluate programs for the promotion of health. I believe that more support should be given to investigators who are prepared to work on these difficult issues of design. This would mean supporting research into research, and I think that in the long run it would be a profitable strategy to adopt.

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